Evaluation of The Robert Wood Johnson Foundation’s Initiative

Ensuring the Consumer Voice in Coverage and Quality in Massachusetts

Year 3 Final Evaluation Report

EVALUATION (ID #61137)

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PREFACE

The recent passage of federal health reform legislation opens extraordinary opportunities for improving the nation’s healthcare system, but much arduous implementation work lies ahead. As the U.S. struggles with the politics and machinery of health reform at a national level, lessons from the various state-level health reform programs already underway will be an extremely important resource. Although rising healthcare costs and state revenue shortfalls have put them on increasingly precarious ground, these programs provide a goldmine of insights into how various approaches to implementing health reform will operate in the field, what they can accomplish, and some possible pitfalls to be avoided.

Groundbreaking state legislation passed in 2006 places Massachusetts at the forefront of state-level experimentation with health reform. As documented in numerous studies, this effort has so far yielded impressive results.\(^1\) Within three years, Massachusetts achieved a state coverage rate of 97.4\%, the highest in the nation. In addition, the state has set new regulatory requirements to improve the quality of care; planning is underway to increase healthcare efficiency and quality through health information technology; and comprehensive changes in the healthcare payment system are being considered by Massachusetts lawmakers in order to bring rising medical costs under better control. While different in structure from the single-payer approach that many consumer advocates have urged as a model for national health reform, Massachusetts’ program clearly offers much food for thought on a policy level, and many of its features are reflected in the recent federal legislation.

This evaluation report focuses not on policy strategies per se, but on another aspect of the Massachusetts experience that may also be useful as a model – that is, the critically important role that healthcare consumers can play in the process of health reform implementation, when they have access to the right kind of support. Part I gives some background on a project sponsored by the Robert Wood Johnson Foundation, aimed at strengthening consumer voice in Massachusetts’ health reform; this introductory section also explains the approach used for evaluation, and briefly describes some drastic changes that took place in the surrounding policy environment as the project unfolded. Part 2 discusses the strategies and activities the grantee organization used to build more effective consumer voice during the project’s three-year funding period. Part 3 consolidates some of the many lessons learned about consumer engagement. Part 4 concludes the report with a few final thoughts on ensuring consumer voice in the future, as national health reform moves forward.

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ACKNOWLEDGEMENTS

Evaluating this complex, rapidly moving initiative would have been impossible without active involvement of the leadership, staff, and consumer partners of the grantee organization, Health Care For All. The evaluator is very grateful for these many individuals’ intelligent input and generous contributions of time, their warmth and humor, their strong commitment to making the project work, and their amazing candor about both its strengths and its problems.

Many thanks are also due to the Robert Wood Johnson Foundation’s program and evaluation officers who oversaw the project, for their flexibility and useful advice as the project and its evaluation evolved.
ENSURING THE CONSUMER VOICE
IN COVERAGE AND QUALITY IN MASSACHUSETTS

PART 1:

INTRODUCTION
BACKGROUND

Many of the interest groups affected by health reform – hospital networks, large insurers, major provider associations, the pharmaceutical industry – are already accustomed to working inside the policy-making system and have developed well organized, heavily resourced machinery for bringing a detailed policy agenda to the attention of government officials and legislators on a systematic, regular basis. This is not typically the case for healthcare consumers, even though they arguably have the most to gain or lose from changes in the healthcare system. When consumers wish to be heard on the subject of health reform, they tend to bring advocacy pressure from the outside, expressing personal opinions through individual letters and calls, petitions, and attendance at one-shot town meetings and speak-outs. These vehicles for expression can and do affect the climate of political debate. However, they do not necessarily connect well with the details of the complex policy changes being considered for the healthcare system, because – as national opinion polls regularly document – most ordinary citizens feel they do not know or understand the details. This leaves them unprepared to express informed opinions on specific aspects of the changes being proposed. After health reform legislation passes, as it has in Massachusetts and a number of other states (and now at the federal level as well), policy-making moves into a world of arcane administrative activities even more unfamiliar to most consumers. At that point, consumer voice is more likely than ever to stay at a symbolic level, easily drowned out or disregarded even if the health reform implementation plan includes formal mechanisms for citizen participation.

But what if healthcare consumers had regular, ongoing access to the kind of detailed background information and sophisticated advocacy resources that allow the large institutional stakeholders in health reform to make their voices heard effectively in policy circles? Could that kind of support succeed in securing a more reliable, informed, and consequential place at the policy table for a strong, continuing consumer voice in health reform’s implementation?

The project evaluated here had exactly that goal: to provide healthcare consumers with the organizational resources and technical supports necessary to participate meaningfully in the flood of detailed administrative and policy decisions following in the wake of Massachusetts’ health reform legislation. This report describes how a grant from the Robert Wood Johnson Foundation was used to promote consumer voice in three key areas of Massachusetts’ health reform – coverage, quality, and e-health (health information technology) – during the project’s three-year funding period of February 2007 to March 2010. Some parts of the project have proved remarkably successful as originally planned. Others have met with challenges calling for practical adaptations and a redirection of strategy. Hopefully, the initiative’s experience will be useful for other consumers, consumer advocates, program sponsors and policy makers who wish to ensure that consumer voice becomes an effective part of health reform decision-making, whether at the state or national level.

ORIGINS OF THE ECV INITIATIVE
Like most ambitious laws, Massachusetts’ health reform legislation, known as **Chapter 58 of the Acts of 2006**,² left numerous important issues to be resolved in the process of implementation. Well aware that devils could be lurking in the details, consumer advocates who had worked to get Chapter 58 passed were concerned that the voice of consumers should be heard loud and clear as the plan went into effect and its various provisions were phased in. They wanted to head off the possibility that, despite the new legislation’s potential for improving health insurance coverage and quality of care, it might in the end fail to serve consumers’ interests adequately because the consumers themselves lacked effective ways of participating in the implementation process.

At the center of this concern was a Boston-based consumer advocacy organization called **Health Care For All in Massachusetts** (HCFA-MA, shortened to HCFA in this report).³ Working with a number of organizational partners and broad-based coalitions, HCFA has for decades played a leading role in Massachusetts health care reform efforts with the stated mission of creating “a consumer-centered health care system that provides comprehensive, affordable, accessible, culturally competent, high quality care and consumer education for everyone, especially the most vulnerable.” As described by its Executive Director at the time of Chapter 58’s passage, the organization seeks to provide “21st century advocacy” – a blend of community organizing combined with legal, technological, research, educational, and care management strategies. HCFA’s resources include diverse kinds of professional expertise, strong policy research capacity, many years’ experience with consumer-oriented advocacy, detailed knowledge of Massachusetts governmental procedures, and well-established working relationships with state officials, lawmakers, healthcare institutions, and consumer advocacy groups. As a public interest nonprofit organization, HCFA engages in active fund-raising and is supported by an ever-changing mix of foundation grants, state funding, and private donations.

Shortly after Chapter 58 was passed, HCFA sought funding to “establish a smart, focused consumer voice to influence both health access reform implementation and the rapidly expanding quality improvement/patient safety movement in Massachusetts.” The request struck a responsive chord within the **Robert Wood Johnson Foundation (RWJF)**, which also has had a long-standing commitment to promoting effective consumer engagement on issues of coverage, access, and quality healthcare. The Foundation undertook to support HCFA’s work through a new initiative titled “**Ensuring the Consumer Voice in Coverage and Quality in Massachusetts**” (abbreviated to “**ECV**” in this report), awarding the organization a three-year grant of $1.5 million scheduled to run from February 29, 2007 to March 1, 2010.⁴ Oversight for the project was provided jointly by two of the Foundation’s program area teams (Coverage, and Quality/Equality and Nursing).

Because the course of Massachusetts’ health reform was impossible to predict with any precision at the time the ECV initiative was launched, the project’s objectives were defined in very

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² The full text of Chapter 58 is available at [www.mass.gov/legis/laws/seslaw06/sl060058.htm](http://www.mass.gov/legis/laws/seslaw06/sl060058.htm).

³ HCFA is located at 30 Winter Street, Boston, MA 02108 (telephone: 617-350-7279). The organization’s website is [www.hcfama.org](http://www.hcfama.org).

⁴ Because Chapter 58 had already been passed and its implementation planning was moving ahead rapidly, RWJF provided HCFA with immediate support while the larger grant was being developed, through a smaller six-month planning grant covering the period September 1, 2006 to February 28, 2007.
broad, flexible terms. By encouraging and supporting consumer voice, HCFA proposed to deliver the following:

- Enrollment of newly eligible individuals and families into appropriate coverage.
- Educational materials about Chapter 58 implementation for the public and policy-makers in Massachusetts and nationally.
- A consumer-driven patient safety and quality improvement agenda for Massachusetts.
- Educational materials to teach consumers about quality improvement in Massachusetts.
- The addition of a consumer voice in key Massachusetts quality councils and other fora.
- Recommendations to ensure that e-health [health information technology] initiatives account for consumer interests.

While specific mechanisms for accomplishing these objectives were not spelled out, the basic goal of the ECV initiative was clear. Rather than advocating as experts on behalf of consumers or simply mobilizing public support for Massachusetts’ health reform, HCFA was to **provide consumers themselves with new skills and supports**, equipping them to make their concerns heard in ways that would be better informed, better targeted, and more effective in actually influencing health reform policy decisions.

**EVALUATION METHODS**

As is usual for RWJF projects, the project has been assessed by an independent evaluator through a consulting contract with the Foundation.

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. It was designed as a collaborative effort, with HCFA’s leadership and staff and some of the project’s consumer partners regularly providing information and helping to shape the evaluation focus as the research went along. RWJF project officers from both the Coverage Team and the Quality/Equality Team also contributed ideas, information, insights, and questions through monthly conference calls with the evaluator. The evaluator integrated all of this input, but remains responsible for overall data collection and development of independent conclusions.

Data on the project have come primarily from three sources:

- **Ongoing review of electronic and print commentary** relevant to HCFA’s consumer advocacy activities, Massachusetts health reform, and health reform issues more generally. HCFA’s own website, e-newsletters and blog provide a steady stream of information, supplemented by blogs of other stakeholders in Massachusetts health reform; state and national government reports; relevant articles published in journals and newspapers; and health reform policy updates and reports on various informational websites.

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5 The evaluator is Carolyn Needleman, PhD, Professor emeritus at Bryn Mawr College. She can be contacted by e-mail at carolyn.needleman@cox.net.
Part 1: Introduction

- **Site visits** to observe HCFA-sponsored consumer advocacy activities in action and have individual discussions with HCFA leadership and staff, some of HCFA’s consumer partners, and various other advocates, experts and state officials connected with the project. In addition to ten in-person visits averaging about 2 days in length, the evaluator has “attended” approximately a dozen key HCFA meetings by speaker-phone.

- **Open-ended telephone interviews** (approximately twelve each month, typically lasting about one hour each) with HCFA staff members who play key roles in the project, HCFA’s Executive Director, and some of the consumers and consumer representatives who work with HCFA.

Mirroring the timing of the initiative itself, the evaluation stretched across three years. During this time, three reports were produced: **two Interim Evaluation Reports**⁶ 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 on health reform implementation, quality of care, and e-health during the funding period. Instead, selected examples are used to explore the following main themes:

- **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?**

**THE PROJECT’S STARTING POINT**

When the ECV initiative began, Health Care For All was already well established as a consumer advocacy organization. During the lengthy campaign to formulate and pass Massachusetts’ health reform legislation, HCFA had played a leadership role in an influential coalition called **Affordable Care Today! (ACT!)**, which met at HCFA headquarters and drew heavily on HCFA for staff support. ACT!’s diverse membership included some organizations representing large institutional stakeholder groups such as healthcare providers, hospitals and insurers, but was mostly made up of consumer-oriented groups.⁷ These grass-roots organizations

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⁷ For example, HCFA itself; the American Cancer Society; several large community-based organizations and coalitions such as the Greater Boston Interfaith Organization and Neighbor to Neighbor; labor organizations such as 1199, the Service Employees International Union; and specialized occupational groups such as the Artists’ Foundation (a strong voice for workers with intermittent, fluctuating incomes). Other major consumer groups have been added since, such as AARP. Appendix #1 provides a list of current ACT!! coalition members.
acted independently as consumer advocates, but their broad agendas included many other policy areas in addition to healthcare. ACT! gave them an opportunity to come together and coordinate their efforts specifically on consumer interests related to Massachusetts’ health reform plan. “Without the ACT! coalition,” a HCFA staff member notes, “the state’s health reform would probably not have been as much on their radar.”

At the time, HCFA was also staffing other community-based consumer advocacy coalitions that focused on state-level policies dealing with oral health, health disparities, and children’s health. In addition, HCFA maintained a small-scale telephone HelpLine for answering consumers’ questions about health coverage; had strong ties with Health Law Advocates, a public interest law firm that helps consumers with legal problems related to health care; and worked closely with Community Catalyst, a sister organization that works on health-related consumer advocacy at the national level.

So, when the ECV project started, HCFA was already actively engaged with consumers and consumer-oriented organizations. However, generally speaking, the advocacy work itself consisted of fairly “wonky” activity by HCFA’s leadership and staff, most of whom had advanced professional credentials and considerable experience with the political process. The operation was efficient and effective, but it was largely carried out on behalf of consumers rather than by them, channeled through coalition member organizations’ leaders and HCFA’s policy staff and lobbyists. In the words of one HCFA staff member, it was a “grass tops” approach to consumer engagement.

What the ECV initiative made possible for HCFA was a shift in emphasis, aimed at:

• **More direct participation by consumers themselves** in formulating a consumer policy agenda related to health reform and (with HCFA’s help) bringing it to policymakers’ attention.

• **A broadened scope for HCFA’s work with consumers**, adding quality-of-care issues and health information technology to the organization’s earlier focus on expanding coverage through Chapter 58’s implementation.

• **Increased effectiveness for consumer voice**, as HCFA used the grant resources to help consumers focus and express their input more strategically.

As described in the sections that follow, each of the initiative’s three focus areas – coverage, quality, and e-health – required a different approach to consumer engagement. At the same time, as the consumers working with HCFA became more actively involved with health reform policy decisions, important cross-ties and synergies developed for consumer voice in the three focus areas, so that the combined efforts began to interconnect and support each other. This is an important point, because consumer advocacy within each of the three areas separately, without the cross-ties, has a potential for counterproductive “silo thinking” in which gains toward one health reform goal might be achieved without regard for the others (for example, expanding insurance coverage but failing to address healthcare-associated infections as a patient safety issue once consumers use the insurance).
A CHANGING PROJECT ENVIRONMENT

One of the project’s most instructive features is the way it evolved through different phases, requiring different strategies as HCFA staff and the consumers working with them gained experience and confronted unexpected challenges. Because the project’s context is so important to understanding its activities and results, this section briefly reviews some highlights of the ECV initiative’s changing circumstances during the funding period. Dividing the effort somewhat arbitrarily into year-length time periods, three different themes emerge.

Year 1: Capacity Building for Consumer Engagement

In the project’s first year (roughly corresponding to calendar year 2007), Chapter 58 was already well into its planned two-year phase-in period. This was a heady time for health reform supporters in Massachusetts, the culmination of at least two decades of all-out advocacy effort. But now all of the deferred administrative details and legislative gaps remained to be worked out, hopefully with strong consumer participation.

Preparations quickly got underway at HCFA. Using the resources supplied by the RWJF grant, the organization more than tripled its staff, raising the number of employees and interns from approximately 12 full-time equivalents to about 38. This supplied the labor power needed to build capacity for consumer engagement by:

- setting up and staffing new organizational structures for more direct consumer participation.
- recruiting and maintaining networks of interested consumer volunteers.
- familiarizing consumers with the key players and procedures of relevant policy systems.
- providing professional expertise and detailed background information to help consumers convert their general concerns into concrete, relevant, well-targeted policy proposals.
- giving guidance, entrée, and moral support as individual consumers built experience with potentially intimidating activities such as public testimony, media interviews, and meeting personally with state decision makers.

None of this was quick or easy. However, Year 1 ended with strong organizational machinery in place for promoting consumer voice on coverage and quality issues, and at least a foothold for consumer engagement in e-health. As described in Part 2, Year 1’s work had tangible and significant policy impact, affecting both legislation and administrative decision-making. Even

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8 A six-month planning grant from RWJF enabled HCFA to start working toward the initiative’s goals prior to its official start date of February 29, 2007; these earlier activities are included as part of Year 1.

9 The exact number of staff is approximate because of some of the organization’s part-time employees and student interns come and go during the year.
more important, by the end of Year 1, state policy-makers had begun to expect and welcome input from HCFA’s consumer partners, who were growing increasingly well-informed and adept at focusing their concerns strategically.

Year 2: Deeper into the Weeds as New Challenges Arise

Year 2 (roughly the calendar year 2008) marked a change of direction for the ECV project in all three of its focus areas, in response to major events in the policy environment and within HCFA itself.

First, now that Chapter 58 had passed through its phase-in period and was fully in effect, the attention of state officials and lawmakers began to shift to “Health Reform II,” with more emphasis on health reform issues that go beyond coverage expansion – notably, cost and quality. An important new bill (titled “An Act to Promote Cost Containment, Transparency and Efficiency in the Delivery of Quality Health Care” and widely referred to as “the Cost and Quality bill”) was working its way through the state legislature and would be signed into law in August 2008 as “Chapter 305,” becoming the new centerpiece of Massachusetts health reform. As discussed later, some key provisions of this bill reflected consumer-oriented recommendations that had been promoted through the ECV project.

HCFA’s work on filling legislative gaps in health reform continued, but once both Chapter 58 and Chapter 305 were in place, the ECV work of HCFA and its consumer partners started to become more administrative than legislative. The project now had to plunge further into the “weeds” of implementation, monitoring more and more intricate rules and regulations to make sure that hard-won legislative victories on coverage, quality and e-health would actually result in real change. As cost containment became more urgent, the potential grew for interest-based disagreements between consumer groups and other health reform stakeholders in HCFA’s coalitions, and some of the “weeds” began to seem like downright thickets.

Another critically important contextual change was the deepening economic recession, which in 2008 began to erode state revenues throughout the nation. Because of higher-than-expected early enrollment, total first-year public expenditures for Massachusetts health reform had been somewhat higher than anticipated (although per capita costs remained well within projections). This would have been manageable in normal times, but with declining revenues, the state found itself with a serious budget gap. The Governor, legally required to balance the state budget, faced hard choices on what could be cut, and HCFA necessarily became drawn into budget advocacy in order to hold the earlier gains for healthcare consumers.

Complicating the budget picture, Year 2 began with great uncertainty surrounding the fate of Massachusetts’ request for renewal of its Section 1115 Medicaid waiver from the Centers for Medicaid and Medicare Services (CMS), reauthorizing the state’s Medicaid eligibility threshold at 300% of the Federal Poverty Level. Depending on the CMS ruling, Massachusetts could potentially lose some $385 million in federal funding, an amount large enough to have

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catastrophic effects on the state’s ability to finance the health reform program. To everyone’s relief, the waiver approval was in fact forthcoming and the 300% FPL level was ultimately reauthorized for the next three years, but this agreement was not reached in principle until September of 2008 and did not actually become official until December.

Finally, during Year 2, HCFA faced personnel changes affecting not only the ECV project, but the entire organization. Early in February of 2008, John McDonough, HCFA’s Executive Director, made it known publicly that he would be leaving within a few months to take a position in Washington as senior advisor on national health reform for the U.S. Senate Committee on Health, Education, Labor, and Pensions. This committee (at that time headed by Senator Edward Kennedy, whose serious illness was not yet public knowledge) was expected to play a central role in crafting federal legislation for national health reform. Everyone understood the need for and significance of Dr. McDonough’s decision, but in the words of one HCFA staff member, his planned move “sent a quiver throughout the entire health advocacy community.” He had been a prominent figure in Massachusetts’ health reform efforts for many years, and HCFA as an organization relied on him heavily for strategy, government connections, tone-setting, and “visioning.” A national search for a new Executive Director began immediately, but as it turned out, there was a significant time lapse between Dr. McDonough’s departure in May and the official appointment of HCFA’s new Executive Director (Amy Whitcomb Slemmer) in October, 2008. Fortunately, a very capable and experienced member of HCFA’s senior policy staff (Fawn Phelps) agreed to serve as Acting Director in the interim, and the rest of HCFA’s staff were also well equipped to carry on with the organization’s work. Ms. Slemmer’s long history of leadership in consumer-oriented nonprofit organizations prepared her to fill the Executive Director position energetically, once she arrived. Still, this change in HCFA’s top leadership and the lengthy recruitment process itself could not help but require time-consuming internal readjustments.

In addition, a policy staff member whose work had been an important support to the ACT!! coalition left to take a position as director of a consumer-advocacy organization similar to HCFA in New Hampshire; a community organizer working with the project’s quality component planned to leave in order to enter graduate school; and several other young staff members, including the communications specialist, were also leaving to pursue educational goals or for other personal reasons. This kind of turnover was not unusual for HCFA, but in this case it meant replacing staff members whose work was important to the fast-moving ECV project, and the transitions required considerable time and effort to ensure that disruptions would be minimal.

These developments left the ECV initiative challenged, but still going strong. In the project’s second year, as discussed in Part 2, remarkable progress was made toward more effective consumer voice in the areas of coverage and quality, and some progress was achieved even in the more resistant area of e-health. However, it was clear that consumer engagement in health reform would probably become more complicated in the following year if the recession deepened and competing pressures on the state budget increased. Responding to changes in the policy context, HCFA found itself exploring a number of new issues and alliances that had not been anticipated at the project’s start. In addition, during Year 2 the administrative details of health reform implementation started growing more technical and complex, demanding increased sophistication and advocacy support for consumers who wished to have a voice in policy-making.

Year 3: Creative Adaptations and a Broadened Scope of Effort
In Year 3 (roughly corresponding to calendar year 2009), economic pressures increased relentlessly not only for state government, but also for consumer-advocacy organizations and individual consumer volunteers. As donations and grants dwindled in the face of deepening recession, most of HCFA’s nonprofit community-based organizational partners in the ACT!! coalition began to lose resources and staff. Their commitment to working with HCFA on the ECV project’s coverage and access goals remained undiminished, but their available time was stretched thin. At least one of HCFA’s long-time organizational allies was forced to close down its operations entirely. Somewhat similar pressures were being felt by the individual consumer volunteers working with HCFA on quality issues. In response to these realities, HCFA began considering how to streamline the meeting schedules and workgroup structures of its two main forums for consumer engagement, the ACT!! coalition and the Consumer Health Quality Council.

HCFA’s own resources also declined sharply as one of its large multi-year foundation grants came to an end and its annual fund-raising event fell short of its goal. Reluctantly, during the summer of Year 3, HCFA was forced to take a much-dreaded step: 9 HCFA staff positions were eliminated, including several related to the ECV project. As described later, the ECV project’s work on coverage and quality issues continued unabated through extra effort and creative redeployment of the remaining staff. However, project work related to e-health had to be scaled back. The ECV initiative was still solidly in place, but worries began to grow about the end of the grant’s three-year funding period, fast approaching in February 2010.

Meanwhile, health reform decision-making began to call for consumer advocacy and consumer voice more and more urgently. Although strongly committed to the reform program and sympathetic to consumer concerns, the Governor’s administration was now struggling with huge revenue shortfalls and coming under great pressure to find places to cut the budget. Increasingly, a top priority for HCFA and its consumer partners became holding the coverage and access gains of previous years, particularly for vulnerable populations such as legal immigrants. On the quality front, the consumers working with HCFA began to play a new and very important role: following up on compliance with previous legislation and regulation (for example, monitoring hospitals to make sure they actually complied with Chapter 305’s quality-related legal requirements and deadlines for public reporting and consumer support services).

All of this was taking place in the shadow of 2009’s ongoing debates over health reform at the national level. Some kind of Congressional action seemed possible, but no one knew exactly what to expect. Massachusetts consumers especially were unsure about whether national health reform would be in their best interests, since health reform in their own state was already well out in front of the national proposals being discussed. After researching the issue carefully and determining that Massachusetts and its healthcare consumers actually stood to gain greatly if national health reform became law, HCFA undertook a public education campaign to help raise awareness of how national health reform would help Massachusetts residents.

Finally, Year 3 saw growing momentum in Massachusetts for legislative action to contain medical costs. State officials and lawmakers started planning for a comprehensive “Payment Reform Bill” to change the state’s fee-for-service payment system to something more sustainable, and various interest groups (for example, small business firms) clamored for even more immediate quick fixes to control insurance plans’ proposed premium increases, which were
running as high as 35%. With payment reform rapidly becoming the center of gravity for the state’s health reform effort, HCFA set up a new Coalition on Payment Reform as part of its “Massachusetts Campaign for Better Care” (so named in order to emphasize the potential links between cost containment and quality improvement). It was clear that consumer voice was going to have a hard time being heard in policy discussions on cost containment, given the high stakes for provider groups, Massachusetts’ highly concentrated hospital system, and the powerful insurance industry. In order to build on the ECV initiative and support an effective consumer voice in the new policy arena of payment reform, HCFA applied for and received funding from RWJF. The Foundation awarded the organization a two-year $300,000 grant for an initiative titled “Strengthening the Consumer Voice in Massachusetts Payment Reform Activities,” scheduled to begin immediately after the ECV initiative funding period ended.

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With this background information as context, the remainder of the present report deals with the ECV project itself – its actual activities and accomplishments (Part 2); some lessons it reveals (Part 3); and its implications for future efforts to strengthen consumer voice (Part 4).
PART 2:

WHAT WAS ACCOMPLISHED?
CONSUMER ENGAGEMENT IN IMPROVING HEALTHCARE COVERAGE

As noted earlier, HCFA went into the ECV project with a strong advocacy coalition – Affordable Care Today!, or ACT! – already in place. With a slight name change (adding another exclamation point to its title), this coalition remained the centerpiece of HCFA’s consumer engagement efforts on coverage as Chapter 58 moved into implementation in 2007. However, some changes in its internal organizational machinery strengthened consumer voice in a number of ways. With its newly expanded staff, HCFA could now:

• **Supply more staff support for the ACT!! coalition’s direct management.** A full-time Health Reform Coordinator and a Health Reform Associate were assigned to facilitate the coalition’s meetings; stay in close touch with coalition members by e-mail and telephone; organize and staff workgroups; supply action alerts and information concerning ACT!! activities for posting on HCFA’s website and blog; draft public position statements and policy recommendations for discussion within the coalition; set up meetings with state officials and lawmakers; and manage logistics for ACT!! members’ participation at public hearings and open meetings of state agencies. These were not completely new activities. However, the added resources made the coalition operate more actively and smoothly, and also allowed the time needed to plan new strategies for including consumer input.

• **Increase the amount and frequency of communication between the ACT!! coalition and HCFA’s internal advocacy resources.** To support its own consumer-oriented advocacy activities (not directly funded by the ECV grant), HCFA employs a number of full-time policy analysts and research staff members, as well as an experienced government affairs expert, a communications specialist to manage media contacts, and a variety of consultants on special issues such as messaging, data management, and legal affairs. Through the ECV project, these sophisticated advocacy supports became much more accessible to the ACT!! coalition. They were also increasingly necessary, as the procedural issues related to Chapter 58 implementation grew more abstruse and intricate.

• **Schedule regular opportunities for discussion of concerns coming from ACT!! member organizations’ rank and file.** In addition to staffing the coalition as a whole and helping to organize its public activities, HCFA hosted monthly meetings (alternating biweekly) of two smaller subgroups: an ACT!! Steering Committee attended by about 30 to 40 of the coalition’s more active members and a smaller Executive Committee including about a third of the Steering Committee participants. A HCFA staff member explains, “The idea [of these smaller groups] is not to set up a hierarchy, but to give those

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11 The coalition made this slight name change to underscore that consumer advocacy related to Chapter 58’s implementation would need to move in directions somewhat different from the initial efforts to get the legislation passed. As an in-house joke put it, HCFA’s work on Chapter 58 was now entering “Act Two.”

12 Generally speaking, these were the member organizations that had played a leading role in the campaign to pass Chapter 58. As a condition of becoming voting members on the ACT!! Steering Committee, they signed a formal contract committing to contribute time and effort to the coalition and to abide by its written ground rules (discussed further in Part 3 of this report.)
most involved a venue for more discussion.” The frequent meetings encouraged informal conversations and brainstorming about new consumer concerns surfacing within ACT!!’s core member organizations. In addition, the representatives from the coalition’s consumer organizations were regularly able to carry information, emerging strategies and policy proposals back to their own memberships for discussion, returning to later Executive Committee and Steering Committee meetings with feedback for fine-tuning ACT!!’s public policy positions.

- **Staff and give support to ad-hoc volunteer workgroups** that could organize background information and strategy options for discussion at coalition meetings. These issue-specific workgroups were open to any of ACT!!’s organizational representatives or rank-and-file consumers who wanted to volunteer. They varied in number and level of activity depending on what was currently happening in the state’s policy-making machinery. During the project’s first year, the most active workgroup focused on the “affordability” aspects of Chapter 58’s individual mandate. Additional workgroups concentrated on outreach and enrollment, public programs, private insurance, and legislation.

**Working with Consumers on Coverage in Year 1**

Working through these mechanisms, HCFA’s consumer advocacy related to coverage issues began to take on a more “grass-rootsy” tone than before – but with a grass-roots consumer voice that was unusually well informed and well resourced, sophisticated about advocacy strategy, and targeted strategically at the current windows of opportunity for policy influence.

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**Example**

As Chapter 58 went into effect, the state’s newly established insurance exchange (the Massachusetts Health Insurance Connector Authority, usually called simply “the Connector”) was charged with a number of initial implementation tasks, one of the most formidable being to set up an authorized schedule of “affordable” premium rates for the insurance that individual state residents were now required to carry. Obviously, defining this level was going to be a challenge, since no one really knew or agreed on what consumers could comfortably pay for insurance coverage. The Connector’s Board developed a proposed Affordability Schedule representing a best guess based on expert advice, and then embarked on a series of public hearings (as required by Chapter 58) to hear reactions.

The Connector Board expected protests from consumers and consumer advocates who wanted to see the proposed premium rates lowered simply as a matter of principle; some of that happened. But the consumers working through HCFA and the ACT!! coalition used a strategy different from simple protest: They presented detailed information demonstrating that large numbers of consumers would in fact not be able to afford the

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13 If individual state residents were unable to find an authorized insurance plan offering coverage at the affordability level the Connector designated for their income level, they would be exempt from paying the state’s tax penalty for non-compliance with Chapter 58’s individual mandate.
initially proposed rates. The data, gathered through one of ACT!!’s most active members (the Greater Boston Interfaith Organization, GBIO) consisted of monthly budgets from over 600 Massachusetts community residents, showing the amount of disposable income actually available at different income levels after the families’ basic needs were met. The grass-roots character of this carefully executed study caught the attention of the Connector Board members, and also of the journalists covering the hearing.

To reinforce the consumer survey data, the hearing was attended by more than 100 consumers, invited through ACT!! with HCFA’s assistance. Most of them wore colorful T-shirts that showed up dramatically in media coverage, emblazoned with logos identifying their organizations: royal blue for the Greater Boston Interfaith Organization, maroon for HCFA, blue and yellow for Neighbor to Neighbor, orange for the Coalition for Social Justice. They came well prepared for the event, committed in advance to behaving respectfully; their demeanor reinforced the idea that their intentions were constructive. In contrast to the kind of unfocused protest that often stands for consumer voice, their input was strategically aimed at a realistic opportunity for policy influence, presented courteously as a contribution to problem-solving, couched in a credible fact-based format that could be taken seriously, and humanized in a way that caused policymakers to stop and listen.

Subsequently, the Connector settled on an Affordability Schedule lower than what had been originally proposed, set at a level much more realistic for true affordability.

By the end of Year 1, the coverage aspects of the ECV project were visibly bearing fruit in terms of consumers’ influence on policy. The ACT!! coalition was increasingly recognized as a reliable vehicle for organized, informed consumer voice in Chapter 58’s implementation, and the Connector Board and other state agencies sometimes even contacted HCFA in advance to request consumer perspectives and testimony on pending proposals. Following consumer input, a number of administrative proposals did in fact change in ways that reflected ACT!!’s agenda, affecting not only insurance affordability but also the kind of “minimum creditable coverage” required of qualifying insurance plans. For example, early in Year 1, it was not certain that the package of benefits defined as minimum creditable coverage would include prescription drugs; after major efforts by ACT!! and HCFA to support consumer voice at appropriate public hearings and state-house events, this benefit was kept in the plan. On the legislative front, ACT!! developed a set of recommendations to address unmet or emerging consumer needs related to coverage and access, and brought them to the attention of lawmakers.

Meanwhile, as Chapter 58’s new requirements and compliance deadlines were being phased in, two important HCFA advocacy resources began to play increasingly central roles in the ECV project’s coverage work even though they were not directly supported through the RWJF grant:

- **HCFA’s HelpLine** was quickly flooded with calls from consumers who needed enrollment assistance and could not find it elsewhere, because the state’s own call centers

14 The HelpLine’s approach is described in detail in a paper currently under review for *Health Affairs*, also available from HCFA; for copies and more information, contact the HelpLine’s director, Kate Bicego (kbicego@hcfama.org).
and public information websites were still being developed and in any case did not offer the kind of multilingual, personalized counseling available from HCFA. Because the state’s information services were organized to be program-specific and could not answer questions holistically, callers often contacted the HCFA HelpLine even after they had already tried the state lines. Late in the year, as the deadline for compliance with the state’s new individual coverage mandate approached, call volume at HCFA rose to as many as 2,000 calls a week – a 400% increase over the 50-per-week average prior to health reform’s passage. In addition to providing direct consumer service, the HelpLine calls gave HCFA staff a steady flow of real-time information from the field about administrative and operational problems unexpectedly cropping up as Chapter 58’s requirements took effect. This ongoing “ear to the ground” became increasingly useful for focusing ACT!!’s advocacy (and policy-makers’ attention) on policy gaps and access barriers that might otherwise have escaped official notice.

- **HCFA’s interactive blog** assumed increasing importance as a user-friendly central clearinghouse that consumers could access for background and editorial comment on policy issues related to health reform; advance agendas and minutes for relevant government meetings; links to news reports, legislation and major national studies; the time and place of opportunities for public input on health reform; and action alerts for advocacy activities and events being planned by HCFA and the ACT!! coalition. Through the blog, consumers interested in health reform gained a handy source of detailed, continuously updated information that would be very hard to dig out on their own. This put them on a more equal footing with large institutional stakeholders able to employ a full-scale policy research and lobbying staff.

**Working with Consumers on Coverage in Year 2**

In Year 2, some of the project’s coverage work continued to focus on legislation, as HCFA and ACT!! educated potential legislative sponsors about their consumer-oriented recommendations. Consumer voice facilitated through HCFA and ACT!! was particularly active in discussions shaping **Massachusetts’ new “Phase II” health reform bill (Chapter 305)** as it developed, using the same techniques described earlier for Year 1 – meetings with legislators about consumer concerns, testimony at public hearings, citizen attendance at open sessions of state agencies, media reports, and well-informed public position statements at critical decision-making moments. A number of ACT!!’s proposals related to coverage were incorporated into Chapter 305 and eventually became law.

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16 As hits on the HCFA blog increased steadily, it became apparent that policy makers as well as consumers were using it as a key information resource. A HCFA staff member recalls putting a just-released government document out on the blog before it appeared publicly anywhere else, and almost instantly getting a call from a state official to discuss its content.

17 This strategy of helping citizens to access “public secrets” (policy-relevant information not officially secret, but so hard to locate that it might as well be) was used to good effect in citizen participation efforts during the 1960’s. See *Guerrillas in the Bureaucracy: The Community Planning Experiment in the United States*, by Martin Needleman and Carolyn Needleman (New York: John Wiley & Sons, 1974).
Interestingly, as the state confronted more directly the factors driving up healthcare costs, new policy issues arose that required different consumer engagement strategies for the ECV project’s work on coverage. Because of ACT!!’s internal diversity, reaching consensus on the coalition’s public position was considerably more complicated for cost-related issues in health reform than it had been during Year 1, when effort had focused on the widely shared goal of expanding coverage and access.

Example

Proposals for Chapter 305 included some reforms related to conflicts of interest in prescription drug marketing, in hopes of controlling practices that unnecessarily inflate drug costs. On this issue, ACT!!’s consumer-oriented members urgently wanted to see drug costs reined in, so as to make health care more affordable for consumers. Other ACT!! members – in particular, those representing the hospital industry and provider groups – found prescription drug reform hitting a bit too close to home for comfort.

Discussion of this issue within ACT!! still generally unfolded in an atmosphere of mutual respect and underlying trust, with the coalition’s member organizations all understanding that they each have to be answerable to their respective constituencies. However, it began to seem that the coalition might not be able to rally behind prescription drug reform without putting some of its members in an untenable position publicly. The solution worked out for this problem was simple and direct: take the drug issue out of ACT!! by forming a separate coalition to deal with it. Thus a new consumer advocacy tool was born: HCFA’s Prescription Reform coalition, made up of some but not all of ACT!!’s membership, plus some additional groups not part of ACT!! This strategy allowed ACT!! to avoid divisive internal conflicts and concentrate on issues where more consensus existed, letting the Prescription Reform coalition take the lead in advocating for reforms aimed at lowering high drug costs for consumers.18

In addition to ongoing conversations with lawmakers, the project’s work on coverage and access increasingly targeted implementation issues. Some of these involved recurring administrative decision points that were now becoming familiar, like the Connector Board’s annual reassessment of the health reform Affordability Schedule. As in Year 1, the open meetings where this was discussed included strong consumer representation through ACT!!, and while the Connector did authorize a small increase in Year 2’s premiums, the rates again ended up much lower than originally proposed. The Connector Board by now understood the consumers’ point of view. However, ACT!! and HCFA still found it necessary to remind everyone constantly that “affordable” premiums and out-of-pocket costs should be pegged to consumers’ actual ability to pay, not the insurance industry’s rising costs; and that “minimum creditable coverage” should assure the benefits actually needed for adequate health care, not whatever benefit package the insurance industry wanted to offer. It was clear that a strong consumer voice was going to be

18 Two such measures became law with the passage of Chapter 305 (establishing new disclosure requirements for provider conflicts of interest, and curbs on certain pharmaceutical marketing practices such as gift-giving to physicians and hospitals). Two other measures – state-supported “academic detailing” to make healthcare providers less dependent on pharmaceutical sales representatives for drug information, and disclosure of pharmaceutical companies’ research grants to academic institutions – remained on the Prescription Reform coalition’s agenda for the coming year.
necessary for many years to come, even (or maybe especially) for “routine” administrative decisions related to coverage.

Through analysis of HelpLine calls, the ECV project proved especially useful in Year 2 for alerting the state’s administrators to unexpected implementation problems in time to correct some costly mistakes. For example, during the summer, a sudden rush of calls came in about insurance termination letters that consumers were unexpectedly receiving in the mail. On investigation, HCFA learned that consumers enrolled in state-subsidized coverage should have received notices informing them that additional information was needed from them by a certain date in order to confirm their continued eligibility – but unfortunately, through an oversight, these notices had never been mailed. HCFA immediately let state administrators know about the problem, and quick corrective action was taken in time to prevent potentially disastrous consequences (such as unintentionally terminating subsidized coverage for some 15,000 eligible consumers, incurring large administrative costs to re-enroll them, and provoking some very negative media coverage for the state health plan). This kind of useful, timely consumer input on unexpected implementation “glitches” helps explain why HCFA and the ECV project were generally well regarded in state policy circles.

Meanwhile, however, potentially more contentious budget advocacy became increasingly unavoidable for ACT!! Massachusetts, like other states, was feeling the effects of economic recession and declining revenues. As the state budget crisis deepened in 2008 and a July 1 balanced-budget deadline loomed, funding cuts being proposed by the Governor and the state legislature threatened to roll back some of HCFA’s past consumer victories, painfully built up over years. Of special interest for this report, some of the proposed cutbacks would significantly affect the consumer engagement strategies being used in the ECV project’s health reform implementation work. For example, proposals from the Governor and/or legislature included:

- Complete elimination of $3.5 million in funding for a statewide MassHealth Outreach and Enrollment Grant Program\(^\text{19}\) that enables about 45 community-based organizations and 8 larger “network” consumer organizations to help consumers enroll in subsidized coverage and locate appropriate care. As one of the network organizations, HCFA had always relied heavily on this funding stream to support its own outreach activities, including the HelpLine. Without adequate resources, the HelpLine might not be able to continue playing the central role that it by now occupied in the ECV project’s consumer engagement work.

- Draconian cuts for the Department of Public Health, eliminating 30% to 50% in operating funds for some of its health-related programs and also reducing the agency’s administrative budget and staff resources by about 25%. Besides being concerned about the direct effects of these cuts on consumers who relied on DPH services, HCFA worried that, after being stripped so bare, DPH might not be able to play the extensive regulatory role assigned to the agency by Chapter 305 and thus the consumers’ legislative gains would be undermined.

\(^\text{19}\) Ironically, as this cutback was being considered, a major research study carried out at the same time was identifying the state-sponsored Outreach and Enrollment grant program as a key factor explaining how Massachusetts had been able to achieve its high coverage rate. See Stan Dor n, Ian Hill, and Sara Hogan, “The Secrets of Massachusetts’ Success: Why 97 Percent of State Residents Have Health Coverage,” Urban Institute Research Report; November 11, 2009; available at www.urban.org/url.cfm?ID=411987
Part 2: What Was Accomplished?

- Sharp cutbacks in state funding for Massachusetts’ two major public safety-net hospitals, both of which claimed that as a result, they would be forced to eliminate critical community services and perhaps shut down entirely. This issue briefly threatened to cause serious strains within the ACT!! coalition, with some ACT!! members (mostly the community-based organizations) urging an all-out fight to rescind the cuts and others (mostly representatives of non-safety-net hospitals) arguing against special pleading for particular institutions.20

Although it meant carrying the work on health reform implementation into somewhat unexpected territory, HCFA felt there was no choice but to become involved in these budget issues, helping to bring consumer voice to bear on them. Particularly around the proposed public health cuts, HCFA joined forces with the Massachusetts Public Health Association (MPHA) through an eighty-organization coalition called “United We Stand for Public Health.” United We Stand sponsored a series of rallies at the Statehouse aimed at showing consumer concern about the proposed budget cuts. The group also pushed for greater transparency in how the state government would allocate a recent large windfall from the federal economic stimulus program (American Recovery and Reinvestment Act, or ARRA). ARRA had made a temporary upward adjustment to the formula that defines the federal government’s share of Massachusetts’ Medicaid costs, adding an estimated $3.1 billion over the next three years. HCFA and other members of United We Stand hoped these dollars would stay within the state’s health sector, and wanted the public to at least be able to track how the funds were used. They advocated setting up a separate state fund for the new money instead of simply folding it into the general state fund. Consumer organizations working through ACT!! supported these forays into budget advocacy through letters and phone calls, as well as participation in public events organized to show concern.

Eventually, Year 2 saw HCFA and its consumer partners drawn even deeper into unexpected issues of state finance. As the seriousness of Massachusetts’ economic situation sank in, the ECV project found itself at a crossroads in terms of strategies for promoting consumer voice in health reform. The state’s impending budget cuts affected not only health and public health, but also education, housing, police and firefighters, infrastructure, social services, etc. Ultimately, consumers need all of these things for a healthful life. Should the coalition’s goal really be to fight for health reform funding at the expense of all other important consumer needs?

So far, HCFA had encouraged ACT!! to stay within the health/public health arena, feeling this was where the coalition could contribute best. However, pressure was building to find some kind of common ground with advocates working on other consumer issues, so as to avoid zero-sum competition over the state budget. Some of ACT!!’s own consumer-oriented organizations were vigorously making this point, since so many of their rank-and-file members faced urgent problems not directly related to healthcare, such as job loss and home foreclosures. HCFA struggled to find a way of keeping ACT!! focused on health issues without disregarding other consumer concerns, and finally settled on “revenue enhancement” – i.e., tax increases – as the

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20 A compromise was reached in the form of a carefully worded letter to the governor on ACT!! letterhead, not mentioning the two safety-net hospitals specifically but urging state funding support for hospitals and community-based health services across the board. This strategy somewhat satisfied ACT!!’s more militant members while still preserving the coalition’s cohesion, and left member organizations free to take further action on their own if they wished to.
Revenue enhancement strategies were not entirely new for the ECV project. For example, HCFA and ACT!! had worked continuously on:

- **Requirements for “employer responsibility.”** Health reform was supposed to be a “three-legged stool” in which employers, consumers and the state would all carry a fair share of the costs, and ACT!! was determined to hold employers to the bargain.\(^{21}\) The coalition had strongly advocated that Chapter 58’s definition of employers’ “fair and reasonable” contribution to employer-sponsored health coverage should be revisited and revised upward, since it was originally set lower than the national average. Because the idea of increasing costs for business has a hard time gaining traction during a recession, ACT!! now shifted the emphasis to getting an increase in “fair share assessment” penalties (also originally set very low) for large employers who externalize their healthcare costs by relying on state-subsidized health insurance programs.

- **Sales taxes on certain consumer products.** As a strategy to improve public health and at the same time generate funds to support health reform, ACT!! had already encouraged public education and consumer support for additional tax increases on cigarettes. The coalition now pushed for new taxes on other tobacco products, and (although consensus was not yet reached) began discussing taxation of other items such as sugared beverages.

What changed in Year 2 is that – in a significant shift in direction – HCFA became increasingly interested in supporting broad tax reforms not directly related to health reform or public health, such as **increases in the state income tax and/or the general sales tax.** After thoroughly discussing the pros and cons, HCFA’s Governing Board approved the idea that such strategies should be actively explored. Accordingly, in Year 2, HCFA staff established informal links with a large, broad-based advocacy coalition called **“Stop the Cuts,”** which was supporting various kinds of taxation to avoid deep cuts in state funding for a variety of services. HCFA’s hope was that advocacy for revenue enhancement would unite this diverse group around a practical, problem-solving strategy for growing the overall budget pie, benefiting a broad range of consumer interests including health reform. Later in the year, Massachusetts voters did (very reluctantly) support an increase in the state sales tax as a way to maintain essential services.\(^{21}\)

HCFA undertook this new direction as an independent organization, while the ACT!! coalition itself took a somewhat more cautious stand with a public statement “supporting policymakers in creative revenue solutions.” HCFA’s Executive Director affirmed that HCFA and its ECV project would not be diluting established commitments to the main mission of health and healthcare reform. However, a hard reality had to be faced: **Without revenue enhancement, Massachusetts’ health reform could prove unsustainable – and thus, to be realistic, consumer advocacy and consumer voice in health reform needed also to focus on fair and equitable taxes to support the program’s publicly funded components.**

\(^{21}\) Even ACT!! member organizations that were themselves large employers (for example, hospitals) supported efforts to revise the employer responsibility standard upward; their own employer-sponsored health plans already considerably exceeded the requirements for “fair and reasonable” coverage.
Working with Consumers on Coverage in Year 3

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!! made three issues their top coverage priorities for the year, using the same methods previously described to help consumers become better informed and make their opinions known to policy-makers.

On the first of these focal points, restoring state funding for outreach and enrollment, their efforts met with at least partial success. Governor Deval Patrick’s basically sympathetic administration found ways of patching together a plan for funding the state’s overall outreach and enrollment grant program, although at a reduced level. Unfortunately, however, the plan did not continue HCFA’s funding as a “network” outreach center, which put the HelpLine on a more precarious footing – a problem for the ECV project, since the HelpLine was now central to its work. HCFA’s leadership and staff gulped hard, thanked the Governor for funding the overall outreach program so necessary to consumers, and managed to scrape together some support for the HelpLine from general operating funds and a few small grants. Meanwhile, HCFA was receiving an ever-increasing number of calls like this one, described by the HelpLine manager:

*Recently, lots of our calls are coming from unemployed folks with questions about their unemployment extensions. The state’s Medical Security Program is supposed to accompany unemployment insurance for as long as the person is receiving unemployment benefits. But we’re seeing a flood of folks who get unemployment extensions, but still get their medical security coverage terminated. We set up a meeting with the director of the Medical Security Program to discuss what can be done about this problem. It sometimes catches people at the worst possible time. For example, one man was in the middle of dental work, getting dentures. He had 11 teeth pulled, and was all set to get his dentures when his medical security coverage was unexpectedly terminated. The dentures are sitting in a box at the dentist office, and he can’t get them. We’re looking into what his options are and will try to help.*

Later in the year, some welcome funding relief for the HelpLine came through a federal grant HCFA received through the Children’s Health Insurance Program (CHIPRA). Some of those funds were channeled to outreach and enrollment related to children, allowing HCFA to hire a HelpLine telephone counselor to fill one of the positions lost in the previous year’s staff cutbacks.

On the second focal point, maintaining dental care as a covered benefit in the Medicaid program, HCFA and its consumer partners met with a setback. The Governor’s proposed budget for the next fiscal year, which starts July 1, 2010, includes serious cuts in dental coverage for state residents insured through MassHealth (Medicaid). Advocacy continues to get these benefits restored.

On the third focal point, protecting the coverage of vulnerable populations, HCFA and ACT!! came face-to-face with some very difficult choices in advocacy strategy. The population most immediately threatened with loss of quality coverage was a subset of the state’s legal immigrants (“aliens with special status,” or AWSS for short). The “AWSS issue” involved some 28,000 state residents who were non-citizens living in the U.S. legally, generally for years, in
many cases slowly working their way through the long process of obtaining U.S. citizenship. HCFA and its consumer-based coalition partners felt strongly that the state’s commitment to universal coverage should include these legal immigrants as tax-paying state residents, and they saw no defensible reason for cutting them out of the health reform plan. Yet that was the administration’s proposal: take the legal immigrants out of the state’s plan, as a way to cut costs.

In response to strong consumer advocacy for keeping some kind of coverage for this population, the state administration cobbled together a somewhat awkward “Bridge Program” for the legal immigrants. Through this program, an out-of-state private insurance company called CeltiCare agreed to make relatively low-cost health insurance available to them, at least for a limited period. Thus the AWSS group would still have coverage, just not through the state’s own health reform plan. While their premiums would remain the same, there would be fewer benefits, a more restricted provider network, and some higher co-pays. HCFA considered this compromise unsatisfactory and contrary to the state’s obligation for equal treatment of all its residents, particularly since the Bridge Program clearly did not work well. The HelpLine was being swamped with calls from legal immigrants seeking guidance on how to handle the confusing coverage transitions required by the compromise plan; it seemed likely that many AWSS families would fall through the cracks and lose coverage entirely, especially if they were not fluent in English. Moreover, AWSS callers reported that even after enrolling in CeltiCare, they found the company’s network so limited that they had to travel long distances to find providers who could be reimbursed for treating them. HCFA, joined by its consumer partners and many of its allied advocacy organizations, wanted to see the legal immigrants brought back into the state’s own coverage system so as to avoid situations like the following, recounted by HCFA’s HelpLine manager:

To give you an example of the AWSS problem, we heard of a woman who would have been covered for a kidney transplant [before being transferred to the Bridge Program]. She has a willing donor. But now that her coverage changed, no doctor or hospital will do it. After a transplant, you need life-long aftercare and medications, so they only do a transplant if you’re insured for that, and she isn’t anymore. Meanwhile, she needs daily dialysis, which she gets through the safety net.

Since state officials had already taken a firm public stand on transferring the AWSS population out of the state plan, HCFA’s customary “inside the system” advocacy strategy of persuading policy-makers with facts and consumers’ personal stories seemed to have hit a brick wall, at least in the short run. One of HCFA’s long-term organizational partners, a public interest law firm called Health Law Advocates (HLA), proposed a different, more confrontational strategy: a civil rights lawsuit against the Governor on behalf of the legal immigrants. HCFA came under intense pressure to take the lead in the lawsuit, both from HLA and from the many members of its own leadership, staff and Governing Board who felt a moral obligation to defend the AWSS coverage no matter what. Of course, if HCFA did join in the attack strategy of suing the Governor, this would jeopardize years of carefully constructed working relationships and mutual trust with the state administration, and it would then be hard to go back to the “inside” advocacy strategies that had been so effective in strengthening consumer voice through the ECV project work. In the end, HCFA did find a path around the dilemma. Using an agreed-upon “hard cop, soft cop” strategy, other organizations took the lead in filing the lawsuit, while HCFA continued to support restoration of state AWSS coverage using its well-honed advocacy tools for working in less confrontational ways.
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. Most of the new coalition’s member organizations are already active in ACT!!, but HCFA has also invited participation from consumer groups working on state policy related to disabilities, health disparities, and specific diseases. As mentioned in Part 1, **the ECV project’s success in strengthening consumer voice in health reform implementation provides a strong base for a new RWJF initiative titled “Strengthening the Consumer Voice in Massachusetts Payment Reform Activities,”** scheduled to run from February 2010 to February 2012 with HCFA as the grantee organization.

In the **ECV initiative’s coverage component**, the final bottom line as the project came to a close is this:

- **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.

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22 Over the three-year grant period, HCFA’s HelpLine staff have personally facilitated the enrollment of at least 10,500 families into MassHealth (Medicaid) or Commonwealth Care (the state’s subsidized private health insurance program).
• 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.
CONSUMER ENGAGEMENT IN IMPROVING
HEALTH CARE QUALITY

The second major component of the ECV initiative addressed healthcare quality. This part of the project started out only loosely connected to the work on coverage, and it called for a very different approach because promoting consumer voice on quality issues was new territory. HCFA had existing ties to a number of organizations and prominent experts working on healthcare quality improvement, and was able in short order to assemble an impressive Expert Advisory Committee, but an organizational structure for working directly with consumers on quality-related health policy did not yet exist. It would have to be built from scratch.

The project’s funding supplied the necessary internal staff resources for this initial capacity-building task, but now HCFA needed a good strategy for recruiting some highly motivated consumer volunteers. Healthcare quality has a number of different dimensions,\(^23\) not all perceived by consumers as urgent. But one issue felt very powerfully and dramatically by consumers is patient safety (or rather, the lack of it) – healthcare-associated infections, wrong-site surgeries, ineffective or harmful medical interventions, major medication mistakes, and other medical errors that can cause death or permanent emotional and/or physical disabilities. As much research shows, these quality problems are quite widespread in the U.S. and many consumers have personal knowledge of them, either through their own experience or that of a family member.\(^24\) For some personally affected consumers, the initial anger and grief they feel will eventually give way to a wish to keep the same kind of preventable tragedy from happening to others, and at that point they might welcome an opportunity to engage actively with policy-making to improve healthcare quality.

With this in mind, HCFA staff set about locating individual consumers who had personally suffered some kind of life-altering medical error, either themselves or within their families. Some candidates were found almost immediately, close at hand. One of HCFA’s staff members expressed interest and disclosed that a misread breast biopsy had left her with undiagnosed cancer, resulting some years later in a double mastectomy and lifelong heightened cancer risk that might have been prevented. A member of HCFA’s own Governing Board also volunteered; she had recently lost her father to a series of escalating medical errors, with a minor ailment leading to a hospital-acquired infection that caused kidney damage, followed by botched kidney surgery with complications that ultimately proved fatal, all made even more painful at every step of the way by cultural insensitivity and denial on the part of the care providers involved. Through word of mouth and putting out calls to partner organizations, HCFA was able to find other consumers who had this kind of personal experience and wanted to contribute their time. The project’s work on quality issues began to take shape.

\(^{23}\) The Institute of Medicine defines “quality” as care that is “efficient, effective, equitable, timely, safe, and patient-centered.” See To Err is Human: Building a Safer Health System, edited by Linda T. Kohn, Janet M. Corrigan, and Molla S. Donaldson; Committee on Quality of Health Care in America, Institute of Medicine (Washington, DC: National Academies Press, 2000).

Working with Consumers on Quality in Year 1

The initial recruitment process was not quite as easy as simply locating appropriate consumers. HCFA staff wanted to make sure that the group they were organizing would focus on injecting policy-relevant consumer voice into efforts for system change, rather than functioning as legal aid, therapy, or a support group for victims of medical error. HCFA’s new community organizer, hired through the ECV grant, spent time with each potential volunteer empathetically exploring whether a good match existed between what the consumer was looking for and what HCFA wanted to develop. Candidates still feeling too much anger and pain to engage in system change efforts were gently steered away from the project and helped to access the services they needed currently, such as legal aid through Health Law Advocates, ombudsman services through the Betsy Lehman Center for Patient Safety and Medical Error Reduction, or emotional support through an organization called Medically Induced Trauma Support Services (MITSS). In order to reinforce the group’s solidarity as a community of shared experience, interested individuals who had not personally suffered from medical errors were also politely dissuaded from joining as direct members; however, they were offered the opportunity to be added to HCFA’s quality e-news list-serve and to be kept updated on the activities of HCFA’s quality initiative.

After several months of this careful screening, HCFA identified about two dozen consumers who were ready for policy advocacy and passionately committed to using their own encounters with poor healthcare quality to make a difference for others. These became the core members of the project’s Consumer Health Quality Council (CHQC, or “the Council”). The time-consuming recruitment and screening activities continued, and by the end of Year 1 the group numbered about 40 consumer volunteers, with a somewhat larger electronic mailing list. The Council met monthly at HCFA headquarters, in the evening because many of the members worked during the day. It was staffed with two full-time HCFA employees (a policy director for quality and a community organizer), backed up as needed with the rest of HCFA’s staff resources.

Initially, the details of the group’s mission and work plans were almost completely undefined. The Council’s vaguely stated purpose was to put together a consumer agenda for healthcare quality improvement, and then figure out strategies for bringing it to the attention of policy makers. But before that could happen in an organized way, the group’s members had to get to know each other and feel comfortable with sharing painful experiences, so the early Council meetings were devoted largely to telling their personal stories. Emotions ran high as Council members relived the unnecessary death of a loved one, or described the preventable medical errors that had led to their own disfigurement, disabilities, or brushes with death. At this point, the group had no bylaws, designated officers, or internal governance structure. Agenda planning, minutes, and meeting facilitation were supplied entirely by the HCFA staff, who also spent many hours in between the monthly meetings developing policy-relevant background information and knitting the group together with telephone or face-to-face conversations with individual Council members.

In contrast to the ACT!! coalition, the members of the Consumer Health Quality Council were not practiced advocates. Their education level was relatively high and some of them worked in professional jobs, but most (with a few exceptions) were unfamiliar with the

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25 Due to distance and physical disability, not all 40 members regularly attended the general meetings; attendance typically numbered around 15 to 20.
workings of state government, inexperienced with mass media, and very nervous about the idea of public speaking. A big part of HCFA’s capacity-building task, therefore, was to help the Council members focus their efforts, start thinking strategically about system change, and build skills and confidence for educating policy makers and the public about their quality concerns.

With HCFA’s assistance, work began on crafting a written Mission Statement—an important process that helped the consumers clarify their purpose and start examining the policy implications of their personal experiences. The meetings began to include more content related to policy and advocacy methods, organized by the HCFA staff; for example, outside speakers were invited in, and training sessions were held to familiarize Council members with the state’s governmental process and key entry points for consumer voice in policy making. An important turning point in the consumers’ growing confidence was the year’s first joint meeting of their own Consumer Council and the illustrious Expert Advisory Committee for HCFA’s Quality Initiative. At this meeting, which HCFA purposely designed to include an informal buffet dinner and many opportunities for small-group discussions, the consumers and the experts from academia and state government began to feel comfortable with each other on a human level. The Council members found the experts much more approachable than they had assumed, and the Advisory Committee’s members were impressed with the consumers’ constructive goals and grasp of policy issues. One of the Council’s consumers commented later, “Our separate worlds touched, and everyone’s comfort level rose.”

As HCFA saw it, the Council was just getting started in Year 1 and needed a great deal of nurturing and staff support, but the ultimate goal of the ECV project was for consumers to find their own voice. Accordingly, great pains were taken by the HCFA staff to avoid over-control and promote self-determination, even when some of the consumers seemed to want more direction and guidance. The HCFA staff wanted the group to accomplish both task goals and process goals, getting useful work done but also making time for ventilation of feelings and talking about group dynamics. This was a difficult balance to strike and missteps were sometimes made, but underlying goodwill carried the group forward and within a few more months, tangible results began to emerge:

- **A six-point consumer agenda for healthcare quality improvement**, identifying specific policy goals consistent with the Council’s Mission Statement, to be developed into recommendations that the Council hoped would be carried forward by state lawmakers.

- A “**storyboard**” of personal narratives and a series of seven compelling, professional-quality **videotapes** of Council members describing their personal and family experiences in

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26 The CHQC Mission Statement appears in Appendix #2.

27 The Expert Advisory Committee provides conceptual and policy guidance to HCFA on quality-of-care issues. Its members include nationally prominent academic experts, directors of major organizations active in patient safety, and state officials responsible for overseeing healthcare quality. A current membership list appears in Appendix #3. The plan developed in Year 1 was for the Expert Advisory Committee to meet quarterly, twice with HCFA staff only and twice in joint meetings with the Consumer Health Quality Council.
dealing with devastating medical errors and healthcare-associated infections, to be used in educating lawmakers and the public about patient safety concerns.  

- **Written and oral testimony by Council members at a number of key public hearings and state house events**, as well as **interviews for TV and newspapers** recounting their personal stories of poor quality care.

- **Council members’ participation in personal meetings that HCFA arranged with individual lawmakers and state officials** to discuss consumers’ quality concerns.

While the consumers did contribute talents of their own, these activities drew heavily on HCFA’s advocacy skills and resources. HCFA staff developed discussion drafts and talking points based on the consumer’s input, provided guidance and technical support\(^\text{29}\) to produce and publicize the videos, and helped the consumers focus their stories and overcome their nervousness about giving testimony and interviews. The consumers specified the content, but HCFA’s ongoing policy research informed their work and HCFA’s political entree and communication resources gave it “legs” and visibility. **The Council’s consumers could not have presented their input nearly as effectively without the support from HCFA made possible by the ECV project. But at the same time, the “voice” coming through was not that of HCFA’s consumer advocacy experts, but directly derived from the consumers themselves.** The consumers’ agenda reflected their own priorities, their policy proposals focused on the areas that most concerned them, the videos told their stories in their own words, and their personal testimony and media interviews portrayed their own real-life experience.

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**Example**

*As the omnibus bill that ultimately became Chapter 305 took shape, a number of public hearings were held at the State House to allow public input on the numerous issues being considered for inclusion. One of these hearings was a day-long event in September 2007, focused on health care quality. Four of the Consumer Health Quality Council’s members planned to give written and oral testimony on the importance of the patient safety concerns identified in the Council’s consumer agenda.*

*Considerable preparation and group support went into this effort. The consumers wrote up their own testimony, but HCFA staff helped them to focus their personal stories around a clear advocacy “ask” – that is, to link the personal narratives with specific recommendations for policy change. The consumer witnesses shared their testimony in advance at a group dinner with other Council members, and practiced repeatedly to make sure they could deliver it within the strict time limit of three minutes.*

\(^{28}\) The videotapes, called *Stories of Harm*, can be found on YouTube and also on HCFA’s website, [www.hcfama.org](http://www.hcfama.org) (page to “advocacy & policy,” then “health care quality,” then “Stories of Harm”).

\(^{29}\) A great deal of technical assistance for the videotapes came from Boston University students doing a class project for HCFA.
On the day of the hearing, the room was packed with well over 100 legislators, legislative aides, journalists, and advocates for specific issues. The schedule ran late and the Council’s consumers were kept waiting for several hours – not easy, considering that the day was hot and some of them were on crutches or in a wheelchair, but they managed it with aplomb. When their turn to speak finally came, their testimony was a show-stopper. It signaled a definite change of pace from the expert witnesses’ facts and figures that had so far dominated the hearing. The room grew hushed as the Council members told their personal stories of poor quality care, carefully stressing not only their own pain and loss but also the huge preventable costs to the health care system. Legislators in attendance gave rapt attention, nodding their heads, in some cases visibly shocked by what they were hearing.

When the Council’s consumers tell their personal stories in small meetings with individual policy makers, the effect is reportedly even more striking. “You can see it in their faces,” said one HCFA staff member. “We’ve had legislators cry when they hear these stories. And some of them then start telling you about horrible medical errors that have happened in their own families.”

Somewhat to everyone’s surprise, the impact of these efforts was dramatic. In the fall of Year 1, in a major victory for the Council, the consumers’ policy recommendations attracted sponsorship from some of the state’s most powerful lawmakers. Four of their six agenda items were incorporated as provisions in the bill that subsequently passed as Chapter 305, becoming state law. The Department of Public Health was charged with issuing regulations by spring of 2009 to implement these provisions, which established the following mandates:

- Hospitals were required, through the Department of Public Health, to disclose and publicly report infection rates.
- Medical facilities were required, through the Department of Public Health, to publicly report so-called “never events” (more recently referred to as “serious reportable events,” or SREs); in addition, hospitals were prohibited from billing for care needed because of the occurrence of a “never event.”
- Hospitals were required to establish and convene “Patient and Family Advisory Councils” through which consumers would have a voice in improving hospitals’ quality of care.
- Hospitals were required to establish Rapid Response Methods that patients and families, as well as hospital staff, can activate when immediate medical attention is needed by a hospitalized person.

The two consumer agenda items not included in Chapter 305 dealt with provider apologies and patient notification after a medical error has occurred. Concerns from medical providers and trial attorneys had clouded legislative support for these two issues, but the Council was determined to continue advocating for them.

As the year went on, Council members grew increasingly self-assured about giving individual testimony and interviews as their public statements met with a good reception.
Meanwhile, the “Stories of Harm” videos produced by the Council were receiving thousands of hits on YouTube, and were picked up for public education and provider training purposes in Massachusetts and elsewhere as well. The consumers’ extensive storyboard of personal narratives about their experiences with medical error provided a ready resource for posts on the HCFA blog, examples in the HCFA quality e-newsletter, and responses to content requests from media.

In addition, important institutionalized mechanisms were developing for consumer input into policymaking related to healthcare quality, through formal representation on influential state planning bodies. In two enormous coups for the ECV project, one of the Council’s most active consumer members was appointed by the Governor to serve on the Massachusetts Public Health Council (a state entity with final say on healthcare quality regulations developed by the Department of Public Health) and the HCFA staff member in charge of managing ECV’s quality component gained a permanent spot on the Advisory Board of the Massachusetts Health Care Quality and Cost Council (which was established under Chapter 58 to develop the state’s plans for health care quality improvement and cost containment). Both HCFA and the consumers ended Year 1 feeling very proud and a bit amazed about what the ECV project’s quality efforts had been able to achieve in such a short time.

On the less positive side, the internal dynamics of the Consumer Council had started to shift in ways that would need attention in the following year. Because the group’s unstructured nature and ambiguous leadership seemed increasingly problematic, work began on crafting written bylaws and developing a formal governance structure for the Council. Formal elections were held in December to fill newly-created positions of president, vice president, and recorder. Although the impetus for these changes came largely from the consumers themselves, opinions were mixed on whether the move toward greater formalization would ultimately help or hinder the group’s expression of genuine grass-roots consumer voice.

In addition, the group’s time and energy resources started to hit practical limits. The original plan had been to develop additional Consumer Health Quality Council chapters in other parts of the state, to ease travel demands on consumer volunteers who lived some distance from HCFA headquarters and also so that consumer input would not come from the Boston area only. During Year 1, considerable HCFA staff time had gone into travel, community presentations, recruitment of volunteers, and organizational meetings related to this goal. However, the reality was that managing the Boston-based Council itself absorbed most of the resources available through HCFA, leaving little time to develop additional chapters. In fact, just to keep up momentum in the existing Council, the overburdened HCFA staff felt they would need the consumer members to gradually take on more of the routine organizational maintenance tasks themselves. To complicate the issue further, HCFA’s community organizer, who had played a key role in recruiting consumers and facilitating meetings for the Council, had plans to enter graduate school the following year and would need to be replaced during Year 2. In preparing a job description for the replacement person, it became more and more clear that the community organizer’s Year 1 workload had in fact been greater than one person could realistically carry.

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30 “Neglect” of Massachusetts’ western counties has long been a sore point in the state’s consumer advocacy circles, and HCFA particularly wanted to avoid this bias. In addition, it became clear that various regions have different problems related to quality; for example, Cape Cod has a serious shortage of providers, which is not a problem in Boston.
Part 2: What Was Accomplished?

Working with Consumers on Quality in Year 2

After winning substantial support among policy makers for the Year 1 consumer agenda, the Consumer Quality Health Council was faced with a strategy choice during Year 2. Should the group’s effort center on educating lawmakers about additional health care quality concerns? Or, following the passage of Chapter 305 (which was signed into law mid-way through Year 2), should the Council consolidate its gains by concentrating on the implementation of that new law’s quality provisions? Following much discussion and consultation with HCFA staff and the Quality Initiative’s Expert Advisory Committee, the Council decided that the latter should be the main priority. Because long time frames in the legislative process sometimes require early “placeholders,” the consumers still continued discussing additional quality issues\(^\text{31}\) with potential legislative sponsors. However, implementing Chapter 305 became the year’s central emphasis. This decision – very wise in retrospect, because of the complexity of the task – allowed the Council to focus its attention on \textit{making sure that the Chapter 305 quality regulations developed in ways consistent with the consumers’ intent.}

To prepare themselves for Year 2’s work on \textit{administrative rulemaking}, Consumer Health Quality Council members used their meetings to become more informed and share ideas about the implementation details of the four quality-related provisions of Chapter 305 listed above. This preparation (greatly facilitated by HCFA’s staff support and advocacy resources) armed the consumers with models and best practices, information about various approaches to measuring quality, details on the technical ins and outs of reporting procedures, and background on legal issues. As a result, they were able to \textit{present their concerns in a knowledgeable and sophisticated way at DPH’s public hearings on the regulations}, as well as in informal discussion with DPH administrators who serve on HCFA’s Expert Advisory Committee for the Quality Initiative. In addition, just as in legislative hearings the previous year, they got their points across in human terms at regulatory public hearings by \textit{sharing their own dramatic personal stories and serving as visible examples of medical errors’ consequences}. When the DPH quality regulations were issued in final form the following spring, they clearly reflected the consumers’ participation as a counterbalance to other stakeholders such as provider organizations and the hospital industry. Without the Council’s well-prepared consumer voice, the new regulations on healthcare quality would have looked quite different.

In Year 2, like ECV’s coverage component, the project’s healthcare quality component became unavoidably involved in \textit{budget advocacy}. The Consumer Health Quality Council had not concerned itself much with state budget matters during Year 1. However, the prospect of large budget cuts for the Department of Public Health could hardly be ignored, since DPH was charged with implementing Chapter 305’s quality provisions. Without adequate staff, how would DPH be able to do an effective job of developing and enforcing the new regulations? Thus, \textit{to prevent their hard-won gains from unraveling, the Council’s consumers felt it logical and necessary to get involved with budget advocacy as part of their overall quality agenda.} During 2008 and even more actively the following spring, the Council issued letters and public statements

\footnote{For example, reducing hospital-acquired infections by screening high-risk patients for MRSA on admission; requiring “checklists of care” to reduce medical errors in hospitals; and reducing medication errors by convening an expert panel to study their occurrence in Massachusetts and recommend ways to decrease them.}
Concerning the need for restoring DPH’s budget, and Council members presented consumer perspectives on the funding cuts at various public events at the State House.

In another interesting development, the Council’s consumers began to find themselves pulled toward quality issues that went beyond their initial focus on medical errors and patient safety. For example, they were asked to provide state officials with feedback on the website developed by the state’s Quality and Cost Council,32 which allows consumers to compare the area’s hospitals on various quality and cost measures. Their regulatory work during Year 2 also propelled them toward a broader definition of quality care, by involving them with hospital-based Patient and Family Advisory Councils that deal with a wide range of patient concerns related to quality and cost. Thus, as the Council matured, its consumers continued their work on medical errors and patient safety, but began to move into additional areas of system change that fit within a broader definition of healthcare quality.

Year 2 also brought to a head some uncomfortable internal developments for the group, which might best be thought of as growing pains. They are described here in some detail because what happened may be instructive for other consumers and advocates. The Council’s first year had been full of excitement, as consumers whose lives were damaged by medical errors discovered that, collectively and with the support of an advocacy organization, they actually could exercise a meaningful voice in policy-making around patient safety issues. Developing a consumer agenda and presenting it to legislators were clear and concrete goals, and the production of high-impact narratives and videos to present their personal stories of harm had been absorbing and satisfying.

During this initial period, the partnership between the Council’s consumers and HCFA had operated fairly smoothly without much attention. HCFA staff fully embraced the principle of consumer empowerment and emphasized to the consumer members that “this is YOUR Council”; and for their part, the consumers felt very appreciative of the guidance and staff support provided in large amounts by HCFA.

In Year 2, however, as the Council moved out of what all concerned refer to as its “infancy,” internal strains developed. They reflect the kind of organizational processes typical of volunteer organizations in general. The crux of the problem was that, as the newness of the effort wore off, getting the routine organizational maintenance work done became more of an issue and the boundaries of the partnership between HCFA and the Council’s consumers became less clear. Who was ultimately responsible for the Council’s agendas, minutes, recruitment, new chapter development, meeting facilitation, drafting public statements and letters, and general management – HCFA staff, or the Council’s volunteer members? How much control should the Council President have over the group’s agenda, being just one individual with strong ideas of his/her own? Should the Council go off in advocacy directions that might not be consistent with HCFA’s other commitments and strategies?

As these issues became more acute in Year 2, HCFA staff observed ruefully that if the Council had left its “infancy” behind, it was now entering the “terrible twos.” For a brief period, they were in a quandary over how to handle what seemed to be counterproductive behavior in the Council. On the one hand, they felt reluctant to assert control with a heavy hand because of their

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32 A HCFA staff member who plays a key role in the ECV project’s quality component serves as a member of the Advisory Board for this state body. The connection facilitates communication between consumers and policy makers, and is another example of how partnering consumers with an advocacy organization like HCFA can help make consumer voice more effective.
genuine commitment to consumer self-determination. On the other hand, they needed to keep the ECV quality component aimed at its initial goals and consistent with the expectations of its grant funding.

Fortunately, the Council’s consumers themselves wanted to resolve these strains. In one of the monthly Council meetings, the general membership discussed some problematic practices and strongly reaffirmed the concept of a collaborative partnership in which HCFA and the Council leadership worked together in close consultation; this was subsequently backed up by HCFA’s own top leadership. By general consensus, the Council’s elected officers took a more active role in routine work; a decision was made to tighten up the bylaws to correct some areas of vagueness; and more formally structured workgroups were organized around particularly time-consuming project activities. Meanwhile, the newly hired community organizer was settling in and building closer relationships with the group. As the project moved into Year 3, the Consumer Council was firmly back on track and again accomplishing a great deal. Two important factors in this successful outcome were the consumers’ willingness to deal with organizational problems openly, and HCFA’s steady faith in the Council members’ ability to put things right themselves.

**Working with Consumers on Quality in Year 3**

In Year 3, as the effects of economic recession intruded more and more into the Council members’ personal lives, it became harder for these consumer volunteers to contribute their time. Attendance at Council meetings began to fall off somewhat, and it became increasingly difficult to recruit new members. At the same time, HCFA’s own resources for the ECV quality work were also being stretched thinner. Due to HCFA’s layoffs in the summer, the staff members most central to the ECV quality component had to carry more assignments unrelated to work with the Council. In addition, the new community organizer was now needing replacement himself, since he planned to go to graduate school; with HCFA’s financial position uncertain, his position would likely remain vacant, at least in the short run. These problems did not discourage either HCFA’s staff or the Council’s dozen or so “hard core” consumer activists who continued to attend every meeting, but it was clear that some organizational restructuring would be necessary as an adaptation to reduced resources.

The plan worked out was as follows: General Council membership meetings would be held every other month rather than monthly, with the quality e-mail lists and the HCFA blog and website serving to keep everyone informed of quality-related developments and events in between meetings. The substantive project work would be carried out mainly through small workgroups, each consisting of three or four consumer members and a designated consumer leader; they would set their own meeting schedules and report their progress back to the larger group electronically and at the bimonthly meetings. Meanwhile, HCFA staff and the Council’s elected leaders would consult regularly and jointly carry out the organizational maintenance work needed to tie the whole effort together. By way of continuing to educate the public and policy makers, Council members would continue to give testimony at public hearings and interviews for media as needed, and the “Stories of Harm” videos (one of which was now translated into Portuguese) would be adapted and made available to media as Public Service Announcements.
Part 2: What Was Accomplished?

This plan appears to have worked very well for producing tangible results, as described below. However, as Year 3 ended, HCFA and the consumers were discussing a possible return to a monthly schedule; the two-month hiatus between general Council meetings was beginning to seem too long for maintaining group cohesion. In an effort to make things easier for the consumer volunteers, the general meetings are now sometimes being held not at HCFA headquarters (where parking is particularly limited), but in community locations outside of central Boston.

Substantively, the Consumer Council’s work on quality issues continued to produce impressive results in Year 3, with two main focal points. First, building on efforts started the previous year, one of the workgroups collected systematic information about Massachusetts hospitals’ resources and procedures related to patients’ problems with quality of care. This was not easy information to discover; at first, it had been hard to get some hospitals even to respond to inquiries. However, an initial pool of data was eventually put together, consolidated with other information on useful resources gleaned from Council members’ own experience and from partner organizations, and prepared as an on-line consumer guide entitled “The Assertive Patient: A Guide to Speaking Up When You Are Dissatisfied with a Health Care Experience.” This guide represents a much needed support for consumers who experience medical errors and don’t know where to turn.

Second, several workgroups concentrated on the hospital reporting and patient support provisions of Chapter 305, particularly the section related to Patient and Family Advisory Councils (PFACs). PFACs take different forms, but basically they aim to bring together current and former patients and family members who are committed to helping a hospital provide high quality care to its patients, their family members, and the community it serves. A PFAC operates in partnership with its sponsoring hospital, with the participating consumers volunteering their time and the hospital providing staff support, operating resources, and open access to hospital administrators. One example familiar to many in Massachusetts is the very active PFAC at the Dana-Farber Cancer Institute.

Mandated statewide establishment of hospital-based PFACs, as was done through Chapter 305, is a powerful action that no other state has taken so far. It creates a legitimized channel for consumers to present their concerns and ideas to hospital administrators and boards on a regular basis, contributing an ongoing consumer perspective on issues such as infection control, follow-up care, checklists, rapid response teams, etc. If the new requirement is well implemented, consumers will have a seat at the policy table within the hospital itself, instead of only knocking on the policy door from the outside. They will have a permanent formal role in helping to shape hospitals’ quality improvement initiatives and facility planning, affecting what happens for patients and families at the hospital bedside, in the operating room, and in the outpatient examining room. On the other hand, if not well implemented, the PFACs could become simply window dressing.

Recognizing the potential of PFACs for effective consumer voice in hospital quality, the Consumer Council has undertaken to monitor hospitals’ compliance with the new state mandates. Regulations specifying a timetable for PFACs (and also Rapid Response Methods) were issued by the Department of Public Health early in Year 3, requiring all acute-care hospital facilities in Massachusetts to have a clear plan for the establishment of their PFACs in place by September 2009 and to have them actually up and running by October 2010. During Year 3, workgroup

33 The guide is available at www.assertivepatient.org.
members contacted all of the state’s 68 hospitals and requested a copy of their plans; sixty-three have been received to date. The Council will continue to check on hospitals’ progress toward putting their plans into action by the 2010 deadline. While this kind of information is clearly critical for regulatory enforcement, DPH may currently be too under-resourced to manage it, so the Consumer Council’s volunteer monitoring appears to be filling a critical gap in effectively implementing Chapter 305’s mandate for this important patient and family support service.  

In addition, in collaboration with the Massachusetts Coalition for the Prevention of Medical Errors, HCFA’s quality team and consumers are participating in a committee that provides technical assistance for hospitals wishing help with setting up their PFACs, through a set of guides and templates based on successful examples and a series of educational conference calls. To help with public awareness, the Council has recently set up a PFAC webpage with information about PFAC plans, a list of all hospitals in Massachusetts with links to those that have PFAC information on-line, and examples of accomplishments from already existing PFACs in Massachusetts.

In the ECV initiative’s quality component, the final bottom line as the project came to a close is this:

• 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. Through the ECV project, 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.

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34 Similarly, the Council has plans to monitor compliance and inform consumers on hospitals’ public reporting of “serious reportable events” (SREs) and healthcare-associated infections (HAIs), required by Chapter 305 and scheduled to begin in the spring of 2010.

35 Accessible through the HCFA website, www.hcfama.org (page to “advocacy & policy,” then “health care quality,” then “Patient and Family Advisory Councils in Massachusetts: Information for Consumers”).
CONSUMER ENGAGEMENT IN DEVELOPING e-HEALTH

The ECV project’s third focus area, e-health, was somewhat more exploratory. Health information technology (electronic tools for medical record-keeping and treatment planning, often called e-health or HIT) is widely regarded in policy circles as an urgently needed component of health reform. However, efforts to engage consumers directly in HIT development have historically been limited and fairly unsuccessful. The underlying problem is not only the area’s technical complexity, but also the fact that e-health still remains largely hypothetical. Until electronic health information systems are actually put in place and more experience with them accumulates, it is difficult for anyone – experts or consumers themselves – to define in detail what the relevant consumer needs and concerns will be. This situation contrasts sharply with the coverage and patient safety aspects of health reform, where many consumers have first-hand experience and strong ideas about what their needs are. Except for some vague concerns about privacy, people have typically not thought much about how they might be affected by health information technology. The whole subject tends to evoke a “MEGO” response from consumers (shorthand for “my eyes glaze over”).

Still, as the ECV initiative was being planned, it was clear that e-health was going to be very important in health reform sooner or later, and that large sums of federal funding for it might be forthcoming in the next few years. Although at the time no one knew where the effort would lead, Massachusetts lawmakers were showing growing support for legislation to encourage state-wide adoption of electronic medical records. It was also clear that, despite consumers’ current noninvolvement, they had enormous long-term interests at stake and would eventually feel a need to make their voices heard. For all these reasons, both HCFA as the grantee and RWJF as the sponsor wanted the ECV initiative to include some attention to consumer engagement in e-health, even if in a more limited fashion than the project’s main focus on coverage and quality. The idea was to “make a place at the table” for consumer voice in e-health policy making, so consumers would be able to participate in a meaningful way when the right time came.

Accordingly, HCFA used the RWJF grant to create a new part-time staff position for an “e-health consumer advocate,” who would serve as a resource person for clarifying consumer interests and identifying advocacy opportunities related to health information technology. Organizationally, her work on e-health was considered a sub-part of the ECV initiative’s quality component. Because the role of e-health advocate was so new and loosely defined, the person hired for this position in a sense had to construct her own job description as she went along. While she consulted with HCFA’s Executive Director and policy staff, her work was largely independent and self-directed. She had office space at HCFA, but most of her work was done away from HCFA headquarters, working from home or traveling and going to meetings off-site.

Working with Consumers on e-Health in Year 1

During Year 1, the e-health advocate concentrated mainly on putting together the building blocks of her assignment. Her first goal was exploring and raising consumers’ awareness and knowledge level concerning e-health. She started developing an email list of interested consumers and advocates, reporting to this network regularly through HCFA’s electronic
newsletters and blog. Her series of lively “e-Health Consumer Network Lunches” during the year allowed those who attended to watch demonstrations and hear presentations by prominent speakers, talk informally with them afterwards, and gain hand-on experience with some emerging electronic tools. 36 The capstone of these public education efforts was an “e-Health Summit,” a half-day conference intended to be an annual event, organized by the e-health advocate to bring together a wide range of experts and consumers interested in health information technology.

Another large part of her work involved strengthening HCFA’s links with organizations relevant to e-health system planning. Some of these links were at the national level – for example, the Markle Foundation’s Workgroup on Consumer Access to Health Information, and the National Partnership for Women and Families’ Consumer Partnership for e-Health. Others were Massachusetts-based, such as a federal-state Health Information Security and Privacy Collaborative (HISPC) project overseen by the Massachusetts Health Data Consortium, assessing how the state’s privacy and security laws would fit with a statewide electronic health information network. A few consumer-oriented groups expressed interest in privacy and data security issues – for example, the Massachusetts AIDS Action Committee – and the e-health advocate worked regularly with them as well. To forge working relationships with these various organizations, she attended numerous conferences and committee meetings, and often served as a presenter, panelist, moderator, or interviewee to contribute a consumer perspective on e-health.

Most significantly for policy influence, she became involved in a large demonstration project then underway to develop electronic medical record systems in three Massachusetts communities. 37 This project had been launched in 2004 with $50 million in funding from the Blue Cross Blue Shield Foundation, and was overseen by a nonprofit organization called the Massachusetts eHealth Collaborative (MAeHC) which included HCFA’s Executive Director on its Board and Executive Committee. The HCFA e-health advocate became a regular participant in MAeHC’s meetings related to the pilot projects. Her goal was to keep potential consumer concerns visible so they did not get completely lost in technical discussions of how best to interconnect and secure acceptance from the three communities’ providers and hospitals. Partly due to her continual urging, the “consumer councils” specified in the demonstration project’s grant finally got created in all three pilot communities, after several years of delay.

The e-health advocate worked with these local councils and with the pilot projects’ Privacy and Security Committees to push for clarity and simplicity in documents meant for consumers, especially the consent forms for “opting in” and “opting out” of the information systems being designed. Through her, rather than being constructed by experts alone, a number of key documents got the benefit of consumer review and feedback. She also arranged for consumer review and feedback on the plans for “patient portals” – i.e., secure web-based windows that consumers can use to access their own health information. Patient portals had not been included in the pilot

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36 Especially popular lunch sessions featured demonstrations of electronic medical records based on the MAeHC pilot programs; a talk on personal health records by David Ahern, National Program Director for a Health e-Technologies Initiative funded by RWJF; and a talk plus demonstration on an electronic tool (“Health 2.0”) that allows consumers to compare and choose among different approaches for treating common health concerns such as weight management.

37 The three pilot communities are North Adams, Newburyport, and Brockton. For an article describing the demonstration project, see Micky Tripathi, David Delano, Barbara Lund, and Lynda Rudolph, “Engaging Patients For Health Information Exchange,” Health Affairs, March/April 2009; 28(2): 435-443.
projects’ initial electronic architecture, but by the end of Year 1 they were in active development in two of the three community sites.

Example

In one of MAeHC’s pilot communities (Newburyport), HCFA’s e-health consumer advocate helped arrange for some well-prepared consumers to meet with staff of the technical firm contracted to construct the patient portal. This eye-opening event offered a rare opportunity for “nerds” and “real people” to discuss each other’s versions of how to make the portals helpful and user-friendly for consumers. A number of consumer suggestions (not previously thought of by the software designers) were subsequently incorporated. Without the unusually well-informed consumer perspective contributed through the ECV initiative at this early point in planning, the technicians designing the patient portal might have gone ahead with their own best guesses about what was needed, and some major defects would have come to light only after an expensive, hard-to-reverse design investment.

The most important result of her work in Year 1 was to strengthen some basic prerequisites for consumer voice – identifying what specific aspects of e-health most need consumer input; promoting consumers’ understanding of how e-health may affect them; joining planning bodies that positioned her for heightening policy makers’ awareness of e-health consumer issues; and making a convincing argument that consumers need to be taken at least as seriously as other e-health stakeholders as HIT programs develop.

Working with Consumers on e-Health in Year 2

Year 2 saw some extraordinary events for the ECV project’s work on e-health:

• With a speed that surprised even the idea’s supporters, Massachusetts moved toward a statewide mandate for electronic health records. A provision was written into the bill that became Chapter 305, requiring that by 2015 – an extremely short development period for such a complex task – all health care providers in the state must participate in a statewide electronic health information system.

• Toward the end of Year 2, the HCFA e-Health Consumer Advocate was appointed by the Governor to serve on the body created to oversee the e-health mandate’s implementation, known as the Massachusetts Health Information Technology Council. She is the only consumer representative on the 8-member panel.

• The federal economic stimulus bill (ARRA, the American Recovery and Reinvestment Act of 2009) included a very large amount of funding for developing health information technology nationwide – approximately $46.7 billion, most of it to be parcelled out gradually in grants to states over a number of years. The funding was targeted mainly at HIT system development and incentives to encourage provider participation, with nothing specifically designated for including consumers in the process; therefore, the grants
received by Massachusetts might not benefit HCFA’s e-health consumer engagement efforts directly. However, the prospect of large-scale federal funding for HIT certainly energized the state-level planning efforts already underway.

The whole e-health issue was being described by state policy-makers as a runaway freight train that can’t be stopped, even though no one knows exactly where it’s going. Unfortunately, in the rush to get a statewide program up and running, it would be easy to neglect the kind of things that concerned the consumers in MAeHC’s three community-based e-health pilot projects, such as privacy and security, patient portals, and electronic tools for disease self-management and comparing providers on health outcomes. Since these components are hard to add in as afterthoughts once an e-health system is established, having some kind of consumer voice represented at an early point in the planning was becoming more and more critical.

The e-health consumer advocate attempted to use her new position on the Massachusetts Health Information Technology Council to fill this need (although it was clearly going to be an uphill struggle, because this planning body’s discussion focused heavily on technical issues). She also collaborated with the American Civil Liberties Union to push for consumer protection legislation to fill some of the gaps in Chapter 305’s e-health provisions, such as security audits, remedies for information breach, and whistleblower protections.

Meanwhile, she continued the efforts for direct consumer engagement that had been started in Year 1 – presentations at conferences, collaboration with state and national organizations working on consumer issues in e-health, planning a third annual E-Health Summit conference, holding regular e-health lunches, and providing input for analysis and articles on the MAeHC community pilot projects now that their funding period had ended. These activities involved consumers to a degree; but compared to the strong consumer voice coming out of the ECV project’s coverage and quality components, the e-health work seemed much more indirect and remote from direct consumer engagement.

**Working with Consumers on e-Health in Year 3**

In Year 3, HCFA had to make an agonizing decision. The e-health advocate’s **workload was already clearly beyond the capacity of one part-time staff member**. At the same time, although a great deal of policy “rumbling” on e-health was going on, not much real progress was being made on the ECV’s initiative’s central goal of helping consumers express their own consumer voice; there seemed to be **little consumer interest in the subject**, especially in the midst of an economic recession. Under these circumstances, should resources be pulled away from other parts of the project to staff up the e-health component? What made most sense, when both the anticipated federal funding for e-health and the state’s e-health planning process seemed to be slowing down anyway because of budget distractions, and HCFA’s own resources problems were already forcing staff cutbacks?

Very reluctantly, the decision was made to **scale back the project work on e-health**, at least until more resources could be deployed and conditions were more favorable for direct consumer engagement. The e-health consumer advocate’s position at HCFA was eliminated in the summer of Year 3. After leaving HCFA, the person who had occupied that position retained her
Part 2: What Was Accomplished?

seat on the Governor’s Massachusetts Health Information Technology Council, but without an official link to the ECV project.

HCFA continues to follow e-health policy developments from a distance. With major federal funding for e-health scheduled to start flowing soon, the pace of Massachusetts’ state-level planning is expected to pick up. At that point, **if resources allow, HCFA’s leadership and staff hope to re-enter the state’s policy conversations about e-health more directly, and to bring consumers with them.**

In the **ECV initiative’s e-health component**, the final bottom line as the project came to a close is this:

- Through the efforts of the 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 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 genuinely need a connection with the consumer advocacy arena.
ENSURING THE CONSUMER VOICE IN COVERAGE AND QUALITY IN MASSACHUSETTS

PART 3:

WHAT WAS LEARNED?
Part 3: What Was Learned?

The evaluation’s two previous Interim Reports discuss a great many lessons that can be gleaned from the ECV project’s experience, ranging from small practical suggestions on project management to observations about the initiative’s basic assumptions. This section of the final report attempts to summarize what has been learned, consolidating the lessons around five major themes.

**LESSON #1**

**PARTNERSHIPS TO FOCUS AND AMPLIFY CONSUMER VOICE**

*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.

The advantages of this kind of partnership showed up very clearly in the ECV project’s coverage and quality components. Without the support of HCFA’s advocacy resources and decades of experience with health system reform efforts, the consumers working with ACT!! and the Consumer Health Quality Council would not have been able to bring such an organized, focused consumer voice to bear on health system change. They might still have expressed their views to decision makers, but in a less strategic, coordinated and timely manner – almost certainly with less impact on policy. At the same time, the consumers’ direct participation gave HCFA’s staff new insights and advocacy tools they would not have had otherwise, such as the detailed information on family budgets supplied through ACT!! and the incredibly effective “stories of harm” videos, storyboard, and personal testimony supplied through the Consumer Health Quality Council.

The project’s e-health component was not able to generate much direct consumer participation during the funding period; consumers did not seem ready. However, the project does shed some sobering light on just how much such partnerships are going to be needed, if consumer voice is to play a positive role in e-health policy making once health information technology gains greater public visibility. Given the steepness of the learning curve for HIT’s technical aspects and the power of other stakeholders who typically dominate its planning, consumers without an advocacy organization’s support will have a hard time formulating their interests in a way that connects with the intricacies of e-health development. For their part, health reform advocacy organizations need the partnership too, in order to learn directly how the new technology affects consumers and what unanticipated problems might be arising. Combining forces could create the kind of empowered consumer voice needed to ensure that e-health will be used not only for cost containment and efficient billing, but also to improve healthcare quality and promote public health.
PART 3: WHAT WAS LEARNED?

LESSON #2: AIMING AT THE RIGHT GOAL

As a focus for consumer voice, expanding coverage is a starting point rather than an end goal. Expanding coverage remains a central goal and an important focus of effort, and is often cited as the single best criterion of health reform’s success. However, it is not an end in itself. The underlying and more important goal is to ensure that the expanded coverage actually delivers quality, affordable, accessible care that improves people’s health. Without effective parallel advocacy efforts to keep consumers’ out-of-pocket costs realistic and maintain the adequacy and real availability of benefits, rising coverage rates may simply mask creeping underinsurance.

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.”

LESSON #3: THREE SECRETS OF ORGANIZATIONAL SUCCESS

The project revealed three interrelated “secrets of success” for building consumer voice.

First, 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, such as phone calls to participating consumers and consumer organizations before and after meetings to discuss special concerns, informal schmoozing (interactions that strengthen working relationships on a human level), spontaneous unstructured brainstorming sessions, taking time to celebrate successes and share jokes, and diplomatic interventions to smooth ruffled feathers and minimize any internal conflicts emerging in these groups. 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. Despite its importance, this kind of work is hard to describe in a grant proposal and hard to link directly with outcomes, so it could easily be overlooked in planning a project like ECV. However, it does need to be taken into account if consumer engagement is going to be successful.

Second, 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-

38 “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.
Part 3: What Was Learned?

Consuming to manage, such idea exchange ultimately promotes more realistic and credible consumer voice. This principle showed up especially clearly in the ACT!! coalition, where the interests of different member organizations not only diverged but sometimes directly conflicted. Consensus was not always reached and it was sometimes necessary to spin off separate advocacy coalitions to work on issues of disagreement; but through the discussion, all parties at least came to a better understanding of the reasons for disagreement and the tradeoffs involved. The same principle operated for the Consumer Health Quality Council, especially through its regular interactions with the experts and state officials on HCFA’s Expert Advisory Committee for the Quality Initiative. For example, in developing their legislative recommendations, the consumers strongly pushed for a goal of zero for healthcare-associated infections, while some Advisory Committee members felt this was inherently unattainable. The Council’s consumers maintained their support for zero as a “stretch goal,” but they could see the experts’ point.

Third, **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. The Consumer Health Quality Council offers perhaps an even clearer example. In its initial excitement and enthusiasm for unfettered democracy, this consumer group tried at first to operate without any documents defining its structure or procedures. It eventually became clear that some governance tools would help the group’s effectiveness, and a set of fairly informal bylaws was put together by the consumers themselves. It then developed that the document had critical gaps and ambiguities, so the Council’s governance procedures needed to be further clarified and the bylaws tightened up. When that was done, what had looked like serious organizational problems began to subside.

### LESSON #4:

**THE ESSENTIAL ROLE OF OUTREACH**

**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 assistance and supplying 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 firm up these connections with individual callers in a way that actually engaged them in the ECV project, it was necessary for a HCFA staff member (typically the communications director) to meet with them somewhere over a cup of coffee and discuss how their work or their story could help others, empathetically explore their comfort level with going public, and explain the kind of support HCFA could offer to make their contribution easier and more effective. Finding the right
Part 3: What Was Learned?

stories and developing “consumer spokespersons” took an enormous amount of time, requiring multiple phone calls and hours of supportive preparation for the initial story-telling event (such as a press briefing), and then similar time investments for future events.

Besides the HelpLine, some additional forms of outreach that were useful for consumer engagement in this project include community forums; community-based enrollment services; media coverage that connects well with diverse populations; and HCFA’s interactive electronic blog that makes news and information about health reform consumer advocacy available to the public on a regular basis.

Unfortunately, public funding for outreach seems to be a particularly vulnerable aspect of health reform. Especially if short on revenue, state officials may begin to see outreach as a low priority once coverage rates reach high levels, because they assume enrollment has leveled off (even though in reality, the pool is not static and new entrants such as the recently unemployed will continue to need enrollment assistance). In Massachusetts, as noted earlier, strong consumer advocacy efforts were necessary to avert complete elimination of state funding for outreach and enrollment programs. HCFA’s own state funding for outreach and enrollment was cut sharply, leaving the HelpLine dependent mainly on philanthropic funding sources and private donations, plus some unexpected last-minute help through a federal CHIPRA grant.

LESSON #5: THE VALUE OF DOGGED PERSISTENCE

One of the most important lessons underscored by the project is that 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 we have seen, 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 periodically get revisited and perhaps revised (as in the case of the Massachusetts Health Connector’s affordability schedule, which is renegotiated annually).

Consumer engagement continues to be important at all of these decision points. Without it, as the drama of new legislation fades, consumer legislative “victories” are likely to be gradually undermined by weakened regulations, non-compliance, non-enforcement, and lack of public

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39 By the end of this project, almost a third of the requests for consumer assistance coming in to HCFA’s HelpLine were from unemployed callers who had lost their employer-sponsored health insurance along with their jobs, and needed help with finding affordable individual coverage.
Part 3: What Was Learned?

... awareness. Thus if consumer voice in health reform is to be genuinely effective, the activities that support it need to continue more or less indefinitely.
ENSUREING THE CONSUMER VOICE IN COVERAGE AND QUALITY IN MASSACHUSETTS

PART 4:

FINAL THOUGHTS
ENSURING CONSUMER VOICE
IN THE FUTURE

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.

As health reform matures, its scope will necessarily broaden out to address even more fundamental system changes aimed at making U.S. health care not only more inclusive, but also sustainable. This in turn creates new potential focal points for consumer voice – health system payment reform, regulation of pharmaceutical and insurance companies, health information technology, provider training, new treatment models like medical homes and shared decision-making, a rethinking of disease prevention and end-of-life care, and even tax reform to ensure that the public costs of health care can be supported. In these larger arenas, so daunting in their complexity and so dominated by “800-pound gorilla” special interests, will interested consumers be able to participate in a meaningful, constructive way?

The experience of the ECV project suggests an answer: Yes – but only if the consumers have access to detailed policy information, help with identifying entry points into the decision-making process, and support as they develop the needed skills and tools.

Thus this very successful project ends on a sobering note. The most appropriate channel for the supports consumers will need is the nation’s many nonprofit consumer advocacy organizations – and these organizations currently exist in such a precarious grant-dependent, feast-or-famine resource environment that they may not be up to the task.

Community Catalyst (a national organization that partners with HCFA) provides technical assistance and support to state health care consumer organizations, and also recently served as the coordinator for a RWJF initiative (Consumer Voices in Coverage) aimed at strengthening the advocacy capacities of consumer organizations in 12 “leader” states on the verge of state-level health reform. In a thought-provoking report, Community Catalyst’s authors note that:

Consumer advocacy organizations are ready to implement national health care reform....[but] additional resources will be needed to expand to more states, build new expertise and capacities, and handle the increasing volume of work.

To sustain consumer voice over the many years it will take to implement national health reform, they urge a major coordinated funding effort by the nation’s large philanthropic institutions. Ideally, foundation grants to community-based nonprofit organizations would be joined by federal and state grants supporting helplines and other outreach and enrollment activities that help consumers engage with healthcare system changes.

Significant amounts of funding would be needed for a nationwide initiative to strengthen consumer voice in health reform as changes in the U.S. system of health care begin to take hold. However, as the ECV initiative shows, this kind of investment could make a critical difference for ensuring that national health reform genuinely succeeds in improving the health and health care of all Americans.
ENSURING THE CONSUMER VOICE
IN COVERAGE AND QUALITY IN MASSACHUSETTS

APPENDICES
APPENDIX #1

Leading Organizations in the ACT!! Coalition

• AARP Massachusetts
• American Cancer Society
• American Heart/American Stroke Association
• Association for Behavioral Healthcare
• Boston Center for Independent Living
• Boston Medical Center
• Boston Public Health Commission
• Cambridge Health Alliance
• Children's Hospital Boston
• Children’s Health Access Coalition
• Coalition for Social Justice
• Community Catalyst
• Community Partners
• Episcopal City Mission
• Families USA
• Greater Boston Interfaith Organization
• Health Care For All
• Healthcare for Artists
• Health Law Advocates
• Home Care Alliance of Massachusetts
• Joint Committee for Children's Health Care in Everett
• Massachusetts Academy of Family Physicians
• Massachusetts Building Trades Council
• Massachusetts Business Leaders for Quality, Affordable Health Care
• Massachusetts Chapter of the American Academy of Pediatrics
• Massachusetts College of Emergency Physicians
• Massachusetts Communities Action Network
• Massachusetts Association of Community Health Workers
• Massachusetts Council of Community Hospitals
• MIRA Coalition
• Massachusetts Health Council
• Massachusetts Hospital Association
• Massachusetts Law Reform Institute
• Massachusetts League of Community Health Centers
• Massachusetts Medical Society
• Massachusetts NOW
• Massachusetts Organization for Addiction Recovery
• Massachusetts Public Health Association
• National Association of Social Workers, MA Chapter
• Neighbor to Neighbor
• Partners for a Healthier Community
• Partners HealthCare
• Public Policy Institute
• SEIU 615
• 1199 SEIU
• Tobacco Free Mass
• UMass Memorial Health Care
APPENDIX #2

Mission Statement of the Consumer Health Quality Council

The Consumer Health Quality Council is a coalition of Health Care For All. The Consumer Council empowers those impacted by health care quality issues to have a voice in our health care system, to engage fellow consumers to be active partners in their health care and to advocate for high quality, safe, and accessible health care for all Massachusetts residents. Consumer Council members work on a variety of projects focusing on education and advocacy and convene monthly to discuss issues relating to health care quality.
The Expert Advisory Committee brings together experts in the field of health care quality improvement and policy to advise Health Care For All and the Consumer Health Quality Council on their projects, legislative priorities, and outreach. The advisory committee also works closely with the Consumer Health Quality Council to bring a consumer voice to their work.

Alice Bonner, Director, Bureau of Health Care Safety and Quality, Massachusetts Department of Public Health (DPH)

Jim Conway, Senior Vice President, Institute for Healthcare Improvement (IHI)

Elizabeth Daake, Director of Policy Development, Planning and Research, Massachusetts Department of Public Health (DPH)

Susan Edgman-Levitan, Executive Director, The John D. Stoeckle Center for Primary Care Innovation, Massachusetts General Hospital

Tracy Gay, Director, Quality and Patient Safety Division, Board of Registration in Medicine (BORIM)

Paula Griswold, Executive Director, Massachusetts Coalition for the Prevention of Medical Errors

Linda Kenney, President and Executive Director, Medically Induced Trauma Support Services (MITSS)

Pamela Mann, Assistant Director of Programs, The Kenneth B. Schwartz Center

Wendy Parmet, Professor of Law, Northeastern University Law School

Barbra Rabson, Executive Director, Massachusetts Health Quality Partners (MHQP)

Stancel Riley, Executive Director, Board of Registration in Medicine (BORIM)

Winnie Tobin, Communications Director, Medically Induced Trauma Support Services (MITSS)

Joel Weissman, Senior Health Policy Advisory to the Secretary, Massachusetts Executive Office of Health and Human Services