

Health Care For All's Consumer Health Quality Council

Introduction

In 2006, health reform became law in Massachusetts. Health Care For All (HCFA), a statewide consumer health advocacy organization, was deeply involved in advocating for the law. In support of the campaign, HCFA staff conducted house meetings across Massachusetts. The organization heard many concerns about access and about the quality and cost of care. In response, HCFA started a consumer campaign for improving health care quality in the Commonwealth. The crux of this campaign would be the Consumer Health Quality Council (CHQC), a group of volunteers motivated by personal experiences and interested in crafting policy solutions to improve quality. In November 2006 the CHQC met for the first time.

The CHQC Mission Statement: The mission of the Consumer Council is to empower those impacted by healthcare quality issues to have a voice in our healthcare system, to engage fellow consumers to be active partners in their healthcare, and to advocate for high quality, safe, and accessible healthcare for all Massachusetts residents.

Fast-forward to the fall of 2010. The CHQC will celebrate its 4-year anniversary and can proudly look back on a number of accomplishments and look ahead to the work that still needs to be done. This essay highlights the CHQC accomplishments that directly relate to MITSS' mission.

II. Support Through Activism

Most members of the CHQC are drawn to the group as a result of adverse medical events that occurred to themselves or their loved ones. As MITSS well knows, there is a need for support following such events. Many CHQC members did seek out emotional support in the immediate aftermath of the occurrence. Upon joining the CHQC, they found additional support in collaborating with others in advocacy for quality improvements so that others would not have the same experiences they had.

Many individuals joined the CHQC for the purpose of telling their stories in order to raise awareness and make change, and they have had a variety of opportunities to do so. The clearest example of this is the CHQC story bank with video and written stories. The stories are featured on the [HCFA website](#) and have been viewed by consumers, healthcare providers, and legislators across Massachusetts, the U.S. and the world. The media has featured several of these stories and CHQC YouTube videos have been viewed over 75,000 times. One story is told in Portugese, to help raise awareness of medical errors in communities that do not speak English as their first language.

The ability to tell their stories to a broad audience has been a strong source of support and affirmation for several members of the CHQC. It is not easy to tell such emotional stories and it can also be difficult to talk openly about a healthcare experience for fear of offending caregivers (though no names are used in the stories because the purpose is to make change in systems and not to point out individual caregivers or institutions). The

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courage of those who are willing to speak publicly is amazing and, it is hoped, provides some support to the thousands of individuals who have experienced adverse medical events-hope for them that there can be a change for the better and that they can help to make a difference.

III. Assertive Patient

Many members of the CHQC and their loved ones felt lost in the healthcare system in the aftermath of an adverse medical event. They did not know where to go for emotional support, for help in navigating the system when they wanted to make a complaint, or for the assistance of an advocate. It is these experiences that led to the creation of assertivepatient.org. This website was the brainchild and creation of the CHQC. There were already many sources of information on-line regarding how consumers can help to prevent medical errors and infections and how individuals can become more engaged healthcare consumers. But there was very little information for those who have had a difficult healthcare experience. Now, Assertive Patient can help those individuals and their families.

The website gives information on how to speak up when you are in the hospital and once you have left the hospital, tips on how to write a complaint letter, information about patient advocates and attorneys, and a list, with descriptions, of resources for assistance, such as MITSS, the Massachusetts Department of Public Health, the Board of Registration in Medicine, and more. There is also a page with a list of all hospitals in Massachusetts and information about each hospital's complaint procedure. The CHQC members did outreach to all of the hospitals and quickly realized there is no standard complaint process. At some hospitals, it is easy to find out the process, either by calling the main telephone number or going on the hospital's website. At others, it is next to impossible to find this information. The hope is that eventually hospitals across Massachusetts will standardize their processes so that consumers can easily navigate the system. Assertive Patient will continue to be updated. The CHQC also hopes to partner with hospitals to work toward standardizing complaint processes.

IV. Still to Come

The Story Bank and Assertive Patient are just two of the many accomplishments of the CHQC. Legislative advocacy has led to, among other things, the establishment of Patient and Family Advisory Councils at all hospitals in Massachusetts. PFACs are made up of patients and family members who advise the hospital on any number of activities and issues. PFACs can work with hospitals to improve quality of care, transparency, patient education materials, and apology and disclosure procedures following adverse events. As MITSS seeks to spread the word about its work and encourages hospitals to establish programs for providing support to clinicians and to patients and family members, PFACs can play an integral role in making that happen. All Massachusetts hospitals must have PFACs in place by October 1, 2010. The CHQC hopes to work closely with all of the PFACs and with their patient and family members to ensure their success.

There are hundreds of thousands of individuals every year who experience medical errors and infections. This means there are many individuals and families who need support,

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and strategic outlets for making a difference. The CHQC is a pioneering example of providing support for those who have had such life-changing experiences through story telling and advocacy. The CHQC leads the state's consumer advocacy to address existing gaps in the system and to help improve the quality of health care for everyone.