

2011 Work Plan

National Health Council

December 2010



Introduction

In Jim Collins' monograph, "Good to Great and the Social Sectors," the author defines lasting endurance for a non-profit organization as delivering "exceptional results over a long period of time, beyond any single leader, great idea, market cycle, or well-funded program. When hit with setbacks, it bounces back even stronger than before."

One way to create lasting endurance is by building an emotional brand. "A key link in the social sectors is brand reputation – built upon tangible results and emotional share of heart – so that potential supporters believe not only in your mission, but in your capacity to deliver on that mission," Collins wrote.

In 2011, the National Health Council (NHC) will focus on strengthening its emotional brand and enhancing value so that it resonates more strongly with its stakeholders

This work plan outlines activities intended to maintain momentum in the NHC's core areas, while strengthening its brand reputation.

- Mission** The mission of the National Health Council is to provide a united voice for people with chronic diseases and disabilities.
- Vision** We envision a world in which all people receive health care that meets their personal needs and goals.
- Goals**
- To improve the health of all people
 - To increase support for health research
 - To strengthen the community of patient advocacy organizations
- Values**
- Trust, collaboration, inclusiveness, and empowerment guide all aspects of the National Health Council's interactions among the diverse sectors of the health community.
 - We operate with integrity, transparency, and honesty.
 - We are patient-focused and forward thinking, ever mindful of our mission to provide a united voice for people with chronic diseases and disabilities.

Key Priority #1 – Advance patient-focused care, health research, and the patient advocacy movement through the development of targeted public awareness and advocacy initiatives.

Outcome 1.1: Prioritize NHC's policy agenda on an annual basis to make the best use of NHC and member organization resources.

- The Government Relations Affinity Group (GRAG), which is comprised of senior government relations staff from the NHC's patient advocacy organization members patient advocacy organizations (also known as voluntary health agencies or VHAs), will meet each month (except August and December) to identify emerging issues that merit possible comment or action and guide the implementation of NHC advocacy efforts.
- To support GRAG, Issue Teams comprised of representatives from all NHC member categories will meet each month (except August and December) to develop strategies that address major policy priorities and share information.
- Although the NHC's Board of Directors will ultimately determine the NHC's policy agenda for 2011, all members have the opportunity to participate in the policy development process. Based on the results of a policy survey that members completed in 2010, GRAG recommends the following priority areas for inclusion in NHC's 2011 policy agenda:
 - » Health care reform implementation:
 - Focus on three top priorities and ensure federal guidelines for implementation are patient-focused:
 - ◆ Definition of essential health benefits
 - ◆ Health care delivery system reform
 - ◆ Comparative effectiveness research
 - » FDA-related issues:
 - Introduce legislation that will dramatically increase the number of cures and treatments for patients with chronic conditions. The legislation will include:
 - ◆ Creating a pathway for the development and approval of advanced diagnostics
 - ◆ Removing patent-related barriers to development of cures and treatments for unmet medical needs
 - Ensure a patient-focused approach to reauthorization of the Prescription Drug User Fee Act (PDUFA). Priorities include:
 - ◆ Advancing regulatory science at FDA to appropriately approve and regulate 21st Century drugs and devices
 - ◆ Ensuring that the benefit-risk equation takes into account varying levels of risk for people with chronic diseases and disabilities

- » Appropriations issues:
 - Support health programs and research at
 - ◆ Agency for Healthcare Research and Quality (AHRQ)
 - ◆ National Institutes of Health (NIH)
 - ◆ Centers for Disease Control and Prevention (CDC)
 - ◆ Food and Drug Administration (FDA)
 - ◆ Department of Defense (DOD)
 - ◆ Veterans Administration (VA)

- In 2011, for the first time the NHC's policy priorities will also be guided by the results of a survey conducted of health legislative assistants of both parties in both Houses of Congress.
- The NHC's Policy Development Fund (PDF) will support the NHC's commitment to be on the leading edge of current and emerging health research and health care issues. The PDF enables the NHC to augment and complement its efforts in the policy area, including hiring content specific experts.
- The NHC will secure congressional sponsors for the 2011 introduction of the Modernizing Our Drug & Diagnostics Evaluation and Regulatory Networks Cures Solution (MODDERN Cures Solution).
- The NHC will continue to be an active participant in the reauthorization of PDUFA and will educate and inform the patient advocacy community about legislative proposals that may be attached to the reauthorization bill. The NHC will develop its own proposals addressing benefit/risk, advancing biomarkers and adaptive trial designs, and patient-focused drug development.
- The NHC will serve as the patient voice on select boards and commissions to help ensure that all Americans have access to health care that meets their individual needs and health care goals. These boards and commissions include, but are not limited to, the AHRQ Effective Health Care Program's Stakeholder Group and the Brookings Institution's Active Surveillance Implementation Council. The NHC will also continue to work closely with and utilize membership communications streams to educate NHC members about
 - » The Council for American Medical Innovation (CAMI) and the initiative to urge Congress to adopt a national policy agenda to advance medical innovation as a key part of the economic future of the United States.
 - » The Coalition Against Major Diseases (CAMD) and the initiative to make important changes in the drug development process for neuromuscular diseases such as Alzheimer's and Parkinson's.
 - » The Association for the Accreditation of Human Research Protection Programs (AAHRPP) and the initiative to ensure that institutions engaging in human medical research are subject to the highest safety and ethical standards.

Outcome 1.2: Effectively implement the NHC's policy agenda and initiatives on an annual basis to ensure the delivery of quality care for patients.

» The Center for Information and Study on Clinical Research Participation (CISCRP) and the initiative to encourage patient participation in clinical research.

- The NHC will expand the content of and access to HealthResearchFunding.Org, the web database created with input from the NIH that makes information on unfunded but worthwhile research proposals available to NHC members and other potential funding sources.
- The NHC will continue to work with the International Alliance of Patients' Organizations (IAPO). IAPO is a unique global alliance representing patients of all nationalities across all disease areas to promote patient-centered health care around the world.

Outcome 1.3: Prioritize and support the work of international patient-focused care activities on an annual basis.

Key Priority #2 – Strengthen the value of the National Health Council to its stakeholders by enhancing the NHC's emotional brand.

Outcome 2.1: Initiate a program to strengthen the NHC brand to select stakeholders, including members, nonmembers, policy makers, the media, and NHC sponsors.

- The NHC will conduct a gap analysis to identify stakeholder expectations of the NHC and how these expectations align with the NHC's programs and initiatives.
- The NHC will create an ad hoc task force made up of representatives from member organizations and companies to work with NHC staff to develop a program to strengthen the NHC brand.
- The NHC will develop a brand implementation guide to provide a strategic plan for promoting the NHC.

Outcome 2.2: Increase awareness and understanding of NHC initiatives and successes.

- The NHC will increase outreach efforts to the media to obtain greater awareness of the NHC policy agenda, program initiatives, and the Standards of Excellence™ Certification Program.
- The NHC will expand its social media efforts in order to
 - » Solicit more patient stories, specifically from patients whose conditions would greatly benefit from passage of the MODERN Cures Solution.
 - » Create a stronger electronic community by cross-promoting with VHA members.
- The NHC will continue to increase VHA involvement in the NHC/ WebMD Patient Voice Exchange by inviting member organizations to add their voices and expertise to conversations about non-clinical issues of interest to the patient community.
- The NHC will continue to seek ways to enhance the content and look of its quarterly newsletter, *Council Currents*, as a means of educating members and non-members about NHC initiatives. *Council Currents* will be published in an electronic format available via e-

mail and the web. Issues of *Council Currents* will be archived on the NHC's website.

- The NHC will analyze its 2010 track record of public appearances, media placements, invitations, and other measurables in order to track the success of its brand implementation plan and to identify ways to increase the NHC's strategic presence.

Outcome 2.3: Create and implement a plan to measure the NHC's outreach and brand promise recognizing distinct outcomes.

Key Priority #3 – Help grow the ability of member patient advocacy organizations to meet their missions and support the mission of the National Health Council.

- The NHC will continue to support the efforts of current and prospective member VHAs to achieve and maintain full compliance with the NHC's Standards of Excellence™ Certification Program.
- During 2011, the NHC again will issue its two annual benchmarking reports: the VHA Revenue Survey and the Management Compensation Report. In addition, the NHC will re-survey VHAs on the issue of the impact of the economy on their organizations.

Outcome 3.1: Assure that all VHA members achieve the Standards of Excellence™ Certification Program.

- The NHC will continue to provide technical assistance to member VHAs on management, organizational, and governance issues.
- The NHC will continue to provide assistance and information to VHAs to strengthen their abilities to involve their patient constituencies.
- In February 2011, the NHC will host its 24th annual Voluntary Health Leadership Conference, where CEOs of member VHAs and their board leaders share information, identify priorities for the VHA community, and learn from each other.
- The NHC will host its annual Washington Representatives Retreat in early December 2011. This meeting is for senior government relations staff from the NHC's VHA members to promote the exchange of ideas and sharing of common solutions that will enhance the effectiveness and success of VHAs and their government relations activities.
- Members of the NHC's CFO Affinity Group will meet in the spring and fall of 2011. CFOs from the NHC's member VHAs, along with those from members of the National Human Services Assembly, will discuss topics aligned around financial planning, public accountability, and organizational workforce issues.
- The chief medical and scientific officers and research directors from the NHC's member VHAs will meet in the fall of 2011. The group will address issues that include increasing access to and fostering

Outcome 3.2: Enhance the organizational effectiveness of member VHAs.

research on new treatments and cures, technology transfer, and NIH grant allocations.

- Senior communications staff from the NHC's member VHAs and non-profit organizations will be convened at least once in 2011 to address ways to work collectively on topics of mutual interest and need.
- Senior development staff and senior legal staff from the NHC's member VHAs will be surveyed to gauge their interest in establishing new working groups in their respective areas.
- To help promote member organizations, the NHC will publish the 21st edition of *Health Groups in Washington* on a timely basis and within budget, and increase sales by enhancing the information available in the electronic format.

Key Priority #4 – Enhance the capacity of the National Health Council to meet its mission.

Outcome 4.1: Assure that the NHC's budget and other resources are sufficient and clearly aligned to accomplish the strategic plan.

- Resources will continue to be allocated to support the NHC's increased focus on policy development and advocacy, to build the NHC brand, and to enhance its ability to provide expanded member services that increase the value of membership.
- Quarterly reports will be provided to the NHC's Board of Directors that measure progress in achieving the strategic plan's objectives, including information about where resources are being directed and the return on their investment.
- The NHC will continue to enhance its web presence. Revisions and enhancements to the website are planned for 2011. The site will continue to communicate content in a way that more effectively reflects the strategic objectives of the NHC to its target audiences, both internally and externally.

Outcome 4.2: Build the NHC's net assets/reserve fund.

- The NHC will continue to invest available funds according to the Board-approved net asset investment policy. Staff will ensure that the investment of funds is coordinated with the level of net assets and the timing of future expenditures.
- The NHC will investigate new potential sources for targeted funding for specified programs and approach those with relevant interest in NHC initiatives.
- The NHC will make its research database HealthResearchFunding.Org accessible to business and industry members and non-member organizations for a reasonable fee to recoup development costs and cover ongoing expenses.

- The NHC will continue to seek new member organizations that broaden the diversity of the membership and represent key stakeholders within the health sector.
- In 2011, the NHC will utilize a membership prospect database created in 2010 to enhance membership recruitment efforts.
- The NHC will develop and implement a member engagement scorecard to enhance membership retention efforts.
- The Nominating Committee will continue to ensure that the Board of Directors reflects the diversity of the membership and the constituents it serves.
- The NHC will evaluate its performance in achieving the goals and objectives of the 2011-2013 Strategic Plan and report to the Board each quarter.
- The NHC will engage its Board of Directors at each meeting in discussions about the strategic plan initiatives to ensure the plan's continued relevance given potential changing circumstances within NHC's internal and external environments.

Outcome 4.3: Increase organizational diversity and representation across health sectors.

Outcome 4.4: Monitor the implementation of the strategic plan to meet its three-year goals.



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