



**NATIONAL HEALTHCARE  
DECISIONS DAY**  
★ *your decisions matter* ★

National Healthcare Decisions Day (NHDD) 2010  
New York State Coalition

## Outcomes Report

Patricia Bomba, M.D., F.A.C.P.  
New York State Liaison, NHDD 2010  
Chair, NHDD 2010 New York State Coalition  
Vice President and Medical Director, Geriatrics, Excellus BlueCross BlueShield

Penny S. Weller, LCSW-R  
Program Implementation Manager, Geriatrics, Excellus BlueCross BlueShield

## Introduction

### Description of NHDD

National Healthcare Decisions Day is “a collaborative effort of national, state and community organizations committed to ensuring that all adults with decision-making capacity in the United States have the information and opportunity to communicate and document their healthcare decisions” (NHDD Case Statement, 2010). National Healthcare Decisions Day (NHDD) began in 2008 and is an annual event.

NHDD initiatives aim to help Americans understand the need for Advance Care Planning (ACP). Advance Care Planning is the process of planning for future medical care in case you are unable to make your own decisions. NHDD aims to educate Americans about the Advance Care Planning process. These steps that comprise the ACP process are summarized in the “[Five Easy Steps](#)” outlined and discussed on the [CompassionAndSupport.org](#) community Web site. The Five Easy Steps are described below.

### Five Easy Steps:

1. Learn about Advance Directives
2. Remove Barriers
3. Motivate Yourself
4. Complete Your Health Care Proxy and Living Will
5. Review and Update

The Five Easy Steps emphasize the importance of having an individual express their medical preferences, clarify their values and beliefs, select a health care agent or spokesperson to make decisions for them in case they are unable to, and, most importantly, have conversations with their family members and other loved ones about their wishes.

A two sided [flyer](#) and [poster](#) identifying the Five Easy Steps, one side in English and the other side in Spanish. The flyers and posters were available to order and distributed to Coalition members and professionals across New York State via mail. The flyer was also made available on the [home page](#) and the [NHDD New York State Coalition](#) page on [CompassionAndSupport.org](#).

### Benchmark Data on Advance Care Planning Nationally

According to a Pew Research Center study in 2006, approximately 71% of Americans had thought about their end-of-life care treatment preferences, and 95% had heard of a Living Will, but only 29% had formally put their care preferences into writing in the form of a Living Will. In New York State, the Living Will is not a legally recognized document and therefore a Health Care Proxy form is required. In New York a Living Will can only be used to provide “clear and convincing evidence” of a person’s medical wishes for end-of-life care. When New Yorkers complete a Health Care Proxy form they are assigning someone to make medical decisions for them in case they are unable to do so.

## National Healthcare Decisions Day in New York State

### Creation of the NHDD New York State Coalition

In New York State the liaison for NHDD 2009 and 2010 was Dr. Patricia Bomba, vice president and medical director, geriatrics, for Excellus BlueCross BlueShield and leader of the Community-wide End-of-life/Palliative Care Initiative. Dr. Bomba coordinated the creation of the NHDD 2009 New York State Coalition which is comprised of 126 organizations from across New York State (NYS). The 161 organizations that collaborated on NHDD 2010 are listed on the [NHDD NYS Coalition Collaborators](#) web page of CompassionAndSupport.org. View the complete list of Coalition Collaborators in 2010 [here](#).

### Benchmark Data on Advance Care Planning in New York State

The best available data regarding Health Care Proxy completion in New York State was collected in 2008 through a telephone survey of Upstate New Yorkers commissioned by Excellus BlueCross BlueShield. The survey found that 88% of adults believe that it is very/fairly important that they have someone who could make medical decisions on their behalf if they were no longer able to do so. Yet, only 42% of adults surveyed had actually completed a Health Care Proxy and designated a health care agent to assume responsibility for making medical decisions. There is clearly a disconnect between the values of Upstate New Yorkers (88% said that it was important) and their actions (only 42% actually did something about it). The NHDD 2009 and 2010 New York State Coalition aimed to address both issues to improve awareness and completion of Health Care Proxies among New Yorkers overall. The complete results of the survey are described in the [End-of-Life Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions, Summary Report, 2008](#).

### NHDD New York State Coalition Goals

Based on the data available regarding knowledge about Advance Care Planning and Health Care Proxy completion, the NHDD NYS Coalition identified three key goals for NHDD 2010. They are:

- Increase conversations that lead to completion of Health Care Proxies
- Increase awareness of the [MOLST Program](#) in the community
- Ensure that [Family Health Care Decisions Act](#) (FHCA) is passed in 2010

### NHDD New York State Coalition and NHDD Subcommittee Meetings

The NHDD NYS Coalition continued to meet monthly for the remainder of 2009, once April 16, 2009 passed, identifying best practices, lessons learned and began to prepare for NHDD 2010. During the last half of 2009, the NHDD NYS Coalition identified two additional topic specific subcommittees. The Family Health Care Decisions Act and NHDD Rochester Region subcommittee had come to fruition. These addition subcommittees would knowingly enhance the already robust NHDD NYS Coalition. The subcommittees and their goals and objectives are as follows:

1. NHDD NYS Colleges and Universities Coalition Subcommittee  
**Goal:** Increase conversations that lead to completion of health care proxies among college and university students.  
**Objectives:**

- Empower college and university students to develop and implement activities and events that achieve the goal.
- Develop a strategy and plan to integrate information on the value of Health Care Proxies, including the Advance Care Planning Booklet, into the admissions process for incoming freshman in NYS colleges and universities.

The subcommittee leaders, Mary Beth Morrissey, a current NHDD NYS Coalition member, along with two student co-leaders, Teddy Morrissey and Duane Brown.

## 2. NHDD Diverse Populations Coalition Subcommittee

**Goal:** Increase conversations that lead to completion of health care proxies within diverse populations in New York State.

The leader, Alfredo Gonzales and Debbie Stamps, are current members of the NHDD NYS Coalition. Bea McCloud is co-leader.

In January 2010, the NHDD NYS Coalition agreed that monthly meetings continue to be most effective. The subcommittees created in the beginning of 2009; the NHDD Family Health Care Decisions Act (FHCDA) Coalition subcommittee and the NHDD Rochester Region Coalition subcommittee met on an as needed basis for 2010. The goals remained the same as 2009, to ensure FHCDA was passed in New York in 2010 (since it did not pass in 2009) and increase conversations that lead to completion of health care proxies within and heightens awareness of the Medical Orders for Life-Sustaining Treatment (MOLST) Program. The minutes of each of the groups (for both the NHDD NYS Coalition and the subcommittees) are available on the [NHDD New York State Coalition](#) page on CompassionAndSupport.org.

### The Role of CompassionAndSupport.org

Throughout NHDD 2010 (as in 2009) CompassionAndSupport.org continued to serve as the hub for information about NHDD events and activities across New York. CompassionAndSupport.org also housed the media hits that NHDD events received and provided the NHDD NYS Coalition with practical tools and resources to plan NHDD events and made information about upcoming Coalition meetings available. In 2010, five Web pages were dedicated to NHDD. Three were created in 2009. The two pages and their functions are described below.

- [National Healthcare Decisions Day](#)
  - Lists NHDD activities across NYS, broken down by region and county
  - Organizations could request that their NHDD activities be posted
- [NHDD 2009 New York State Coalition](#)
  - Lists Coalition announcements, meeting schedules, and minutes
  - Informal NHDD plans and ideas from across NYS are posted here for others to use in developing their own plans and ideas for NHDD activities
  - Tools and resources for planning NHDD events are posted
  - Tools and resources for supporting FHCDA are posted

- [NHDD 2009 New York State Coalition Collaborators](#)
  - Lists all organizations collaborating in NHDD 2009 in NYS
  - Organizations interested in becoming collaborators could request to be listed

Two additional web pages were created for NHDD 2010 on CompassionAndSupport.org. The two pages and their functions are described below.

- [NHDD 2010 Colleges and Universities Coalition](#)
  - Lists Coalition announcements, meeting schedules, and minutes
  - Tools and resources for supporting NHDD, Colleges and Universities events are posted
  - Lists events and activities by New York State region and name of scholastic institute. Includes link to summary or flyer of each event
- [NHDD NYS Coalition - Archived](#)
  - Lists NHDD NYS Coalition; Outcomes Report, Collaborators, goals, legislative testimony, Statewide events and activities, Regional events and activities, event plans and ideas, common event resources and activities in the workplace.

### **NHDD 2010 Data Collection and Reporting**

In the first NHDD NYS Coalition meeting in January 2009, agreed to create an annual formal report describing each NHDD year's activities in New York State and outlining annual data collected. The initial [NHDD NYS Coalition Outcomes Report](#) was made public in 2009 on the [CompassionAndSupport.org](#) community Web site. This report is the culmination of data collection each calendar year regarding NHDD activities and outcomes. The NHDD NYS Coalition believes that this report will create a strong evidence base to support continued education on advance directives and Advance Care Planning in New York and would reflect the collaboration and leadership across New York State as a part of NHDD. To accomplish this, an [electronic survey](#) was distributed to the NHDD NYS Coalition to collect data on the variables discussed below. The data was compiled, analyzed and summarized into this report.

It is important to note that the results of this survey are simply a snapshot of all of the NHDD activities that took place in New York State. The survey results relied heavily upon individuals responding to the survey and are not a complete reflection of all of the activities that took place. Given the methodology that we used these are the best estimates of what took place surrounding NHDD in New York State in 2010.

## **NHDD 2010 Follow-up Survey**

### **Survey Objectives**

The NHDD 2010 Follow-up Survey was intended to collect data about NHDD 2010 events and activities throughout New York State. Data was collected on a number of different variables including:

- Types of organizations that participated in NHDD
- Types of NHDD activities and number of participants per activity
- Venues for NHDD activities
- Number of people who completed an advance directive during an NHDD activity
- Media and advertising utilized to promote NHDD activities
- Media and news coverage provided on NHDD activities
- Evaluation of NHDD activities
- Evaluation of the NHDD New York State Coalition

### **Methods**

Links to the online NHDD 2010 Follow-up Surveys were distributed via email to all members of the NHDD New York State Coalition as well as anyone who participated in the NHDD NYS Coalition meetings or was included on the NHDD NYS Coalition electronic mailing list due to their role as a healthcare leader in New York State. In Overall, Dr. Bomba emailed the link to the 2010 survey to 470 individuals, or 10% response rate, as compared to 2009, which yielded 27 completes or 6.4% response rate. It is worthy to note that many of these individuals participated in several organizations and/or coalitions across the state and therefore while 470 individuals received the survey the number of unique organizations and coalitions represented in the survey mailing was significantly fewer. Dr. Bomba sent out one reminder email to all 470 individuals several weeks after the initial email requesting completion of the NHDD 2010 Follow-up Survey was sent.

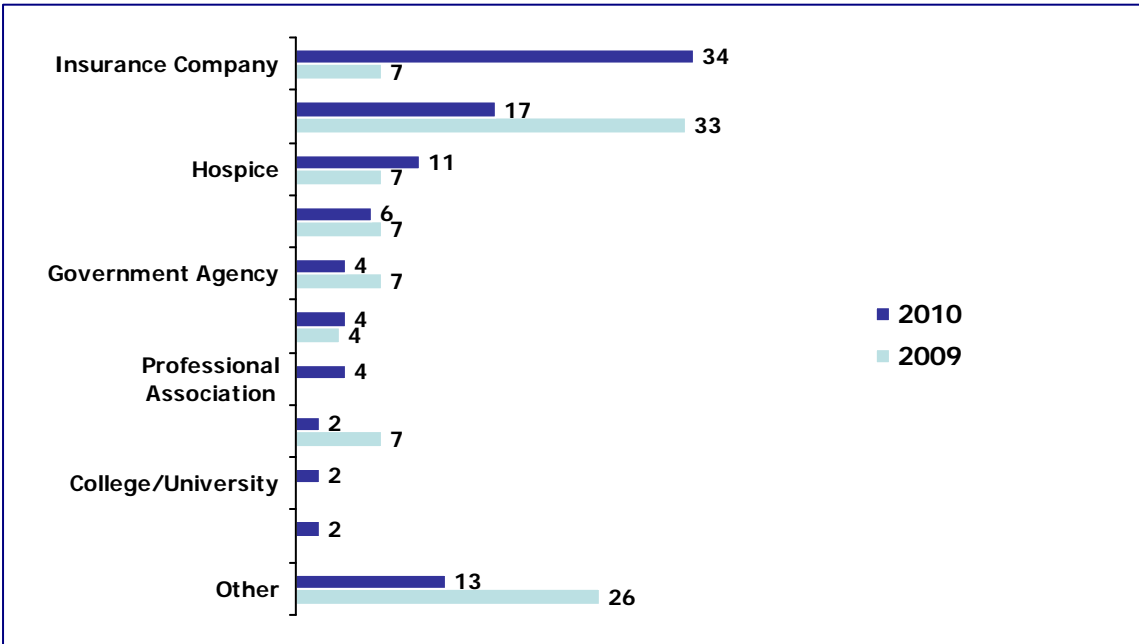
### **Survey Response Rates**

Of the 470 individuals who received the survey the response rate was approximately 10%, with 47 individuals completing the survey. Again, it is helpful to understand that the individuals who responded to the survey were responding for an organization or coalition. The NHDD 2010 Follow-up Survey responses represented 38 unique organizations and/or coalitions. Given that there are 160 organizations/coalitions on the NHDD NYS Coalition the organizational response rate to the survey was approximately 24% compared to the 19.0% response rate in 2009. The 2010 responses covered 20 of New York State's 62 counties (32%).

### **Organizations that Participated in NHDD**

Responses to the NHDD 2010 Follow-up Survey were received from 38 unique organizations and/or coalitions in total. Responses to the NHDD 2009 Follow-up Survey were received from 24 unique organizations and/or coalitions in total. The following graph identifies the type of organizations that participated in NHDD 2009 and NHDD 2010, showing comparison.

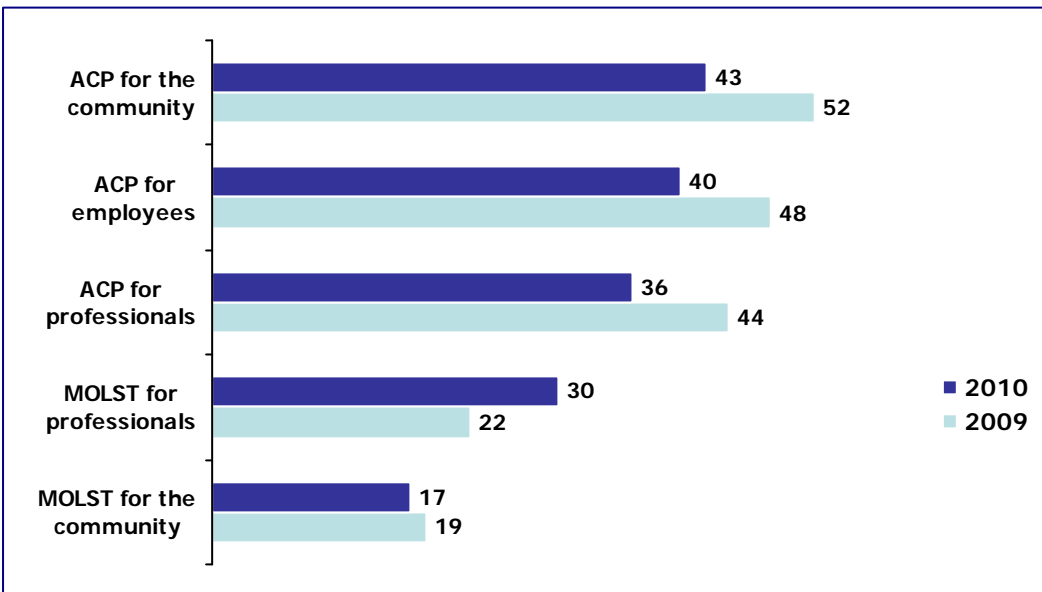
- Type of Organization (% Selecting)



### NHDD Activities, Attendees, and Venues

A breakdown of NHDD activities in terms of which groups of people were educated, what topics were covered, how many people participated per activity, and where the events were held is provided in the tables below.

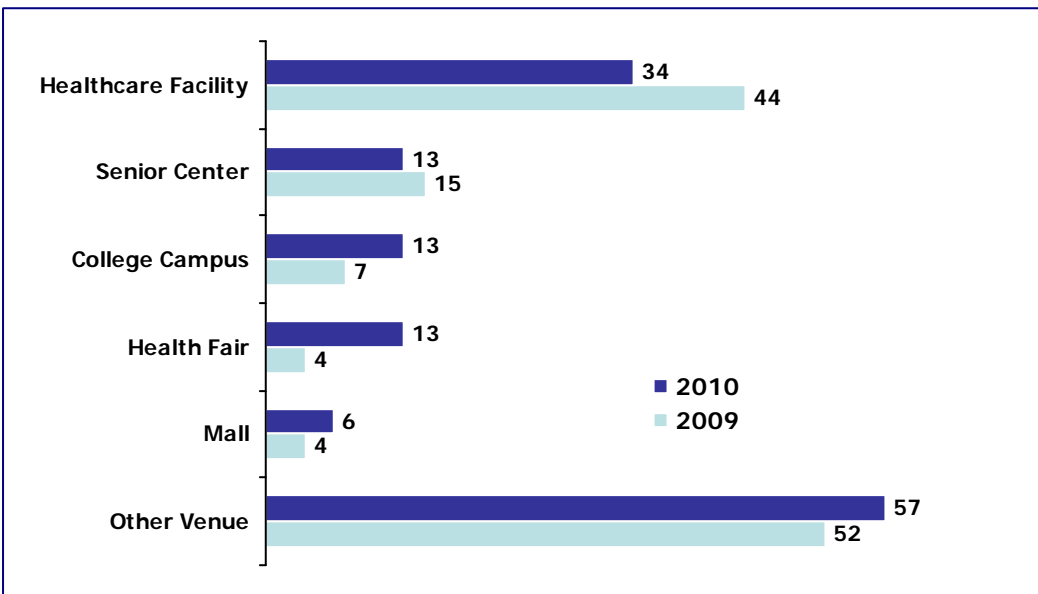
- Involvement in NHDD Presentations on the Following Specific Topics (% Selecting)



- Number of Attendees at NHDD Presentations By Topic (% Selecting)

	1-15 Participants		16-30 Participants		31-50 Participants		51-100 Participants		More than 100 Participants	
	2009	2010	2009	2010	2009	2010	2009	2010	2009	2010
ACP for Employees	7.7	36.8	30.8	21.1	15.4	10.5	23.1	15.8	23.1	15.8
ACP for Professionals	25.0	35.3	8.3	17.6	8.3	5.9	25.0	23.5	33.3	17.6
ACP for the Community	21.4	30.0	42.9	20.0	0.0	15.0	28.6	0.0	7.1	35.0
MOLST for Professionals	16.7	28.6	16.7	14.3	0.0	14.3	0.0	28.6	66.7	14.3
MOLST for the Community	20.0	75.0	60.0	12.5	0.0	12.5	20.0	0.0	0.0	0.0

- Venues Used for Advance Care Planning Education (% Selecting)



The “other” venues for holding NHDD activities primarily fell into one of the following categories: libraries, adult housing facilities, and religious centers, county departments of senior services, medical offices, and pharmacies.

The majority of participants in NHDD activities were involved at a healthcare facility or at a venue that fell into the “other” category.

**Highlighted NHDD Activities that Supported the New York State Coalition’s Goals**

There were many NHDD activities that took place in the months around April 16, 2010 and the data surrounding these activities is discussed further in sections below. There are several activities that were specifically aimed at supporting the NHDD New York State Coalition’s goals and deserve to be highlighted given the unique groups involved and the planning and coordination required across New York State – from New York City and Long Island to Upstate, Western and Central New York.

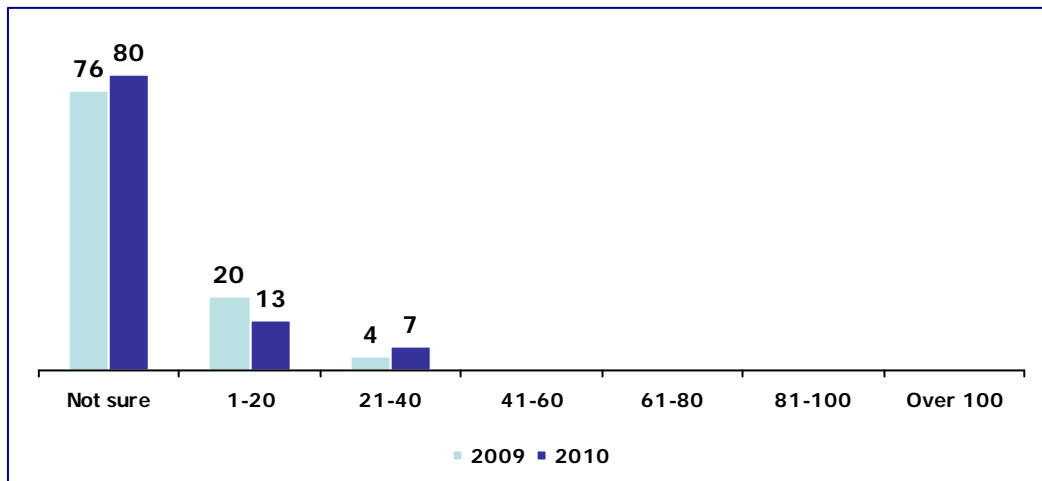
### Activities to Support NHDD

- The NHDD NYS Coalition worked on social media as additional event NHDD resources, such as [Face book](#) and [Twitter](#)
- The Medical Society of the State of New York MSSNY and Excellus BlueCross BlueShield developed a 2010 [public service announcements](#) (PSAs) that have been aired across New York. These six PSAs in English and one in Spanish are focused on educating New Yorkers about the importance of Advance Care Planning and the need to complete traditional advance directives like the Health Care Proxy and Living Will.
- The [Compassion And Support Audio Library](#) was created and is housed on the [CompassionAndSupport.org](#) Web site. Listen to audio clips on various advance care planning topics.
- In May of 2010, the New York State Department of Health disbursed the [Dear Administrator Letter](#) (DAL) across NYS.
- Dr. Bomba hosted two Upstate New York all-day Medical Orders for Life-Sustaining Treatment (MOLST) Conferences. One was held on March 20, 2010 and the second was held on April 17, 2010 at Lifetime Care Homecare and Hospice on 3111 Winton Road South, Rochester, New York, with a total of one hundred and forty-one attendees.
- For further details of events proceeding, during and following the month of April 2010, [view HERE](#).

### Number of Advance Directives Executed

Respondents were asked about whether individuals who attended their activities chose to execute a Health Care Proxy or Living Will on the spot at the event in the table below.

- **Number of Individuals Who Executed Advance Directive(s) On the Spot (% Selecting)**



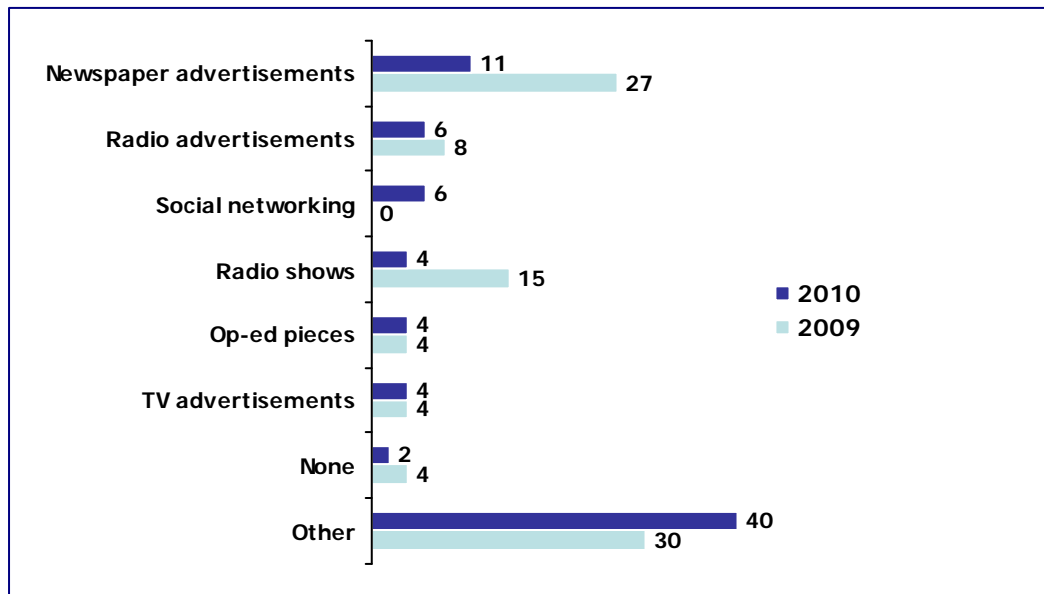
NHDD activity organizers indicated that they were primarily focused on helping people understand the importance of having a conversation about their future healthcare wishes and encouraging them to sit down with their families at some other point to complete the forms. This approach to NHDD events is in line with the Five Easy Steps method to complete Advance Care Planning and is preferred by the NHDD NYS Coalition. The Coalition believes that it is preferable to have people *not*

execute advance directives on the spot, and rather go home and have a thorough conversation with their health care agent, family, and loved ones and then complete the forms.

### Media and Advertising Utilized to Promote NHDD Activities

The top eight types of media and advertising used for NHDD 2010 activities and events are displayed in the table below. Popular methods of advertising were through posters, flyers, and emails to small groups. Newsletters, mass emails, Web site advertisements and press or news releases were also common.

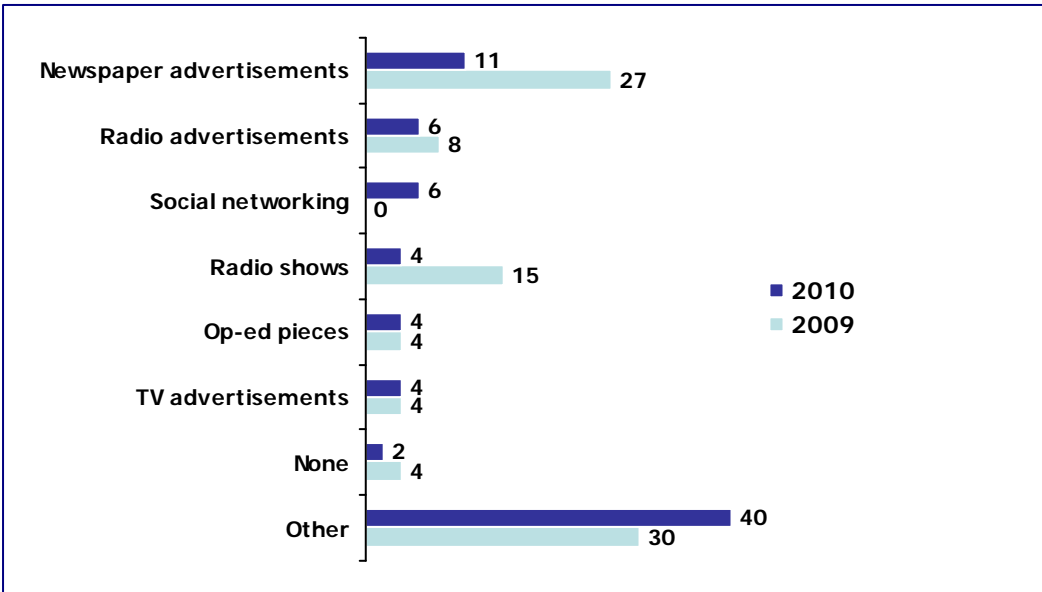
- Top 8 Types of Media and Advertising Used (% Selecting)



### Media and News Coverage Provided on NHDD Activities

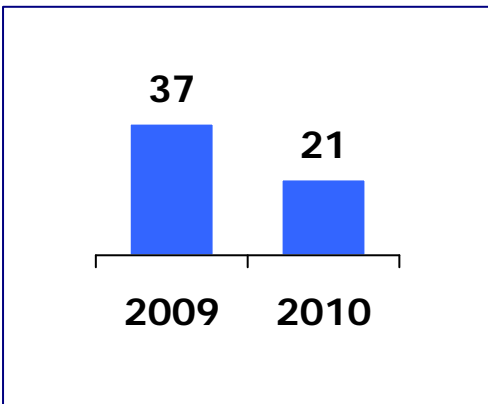
According to the NHDD 2010 Follow-up Survey, respondents were requested to provide links to the media or news coverage if it was available online. These links were then included in a special NHDD section on the Current News page of CompassionAndSupport.org. If notice of media and news coverage was provided to CompassionAndSupport.org staff outside of the survey then those media hits were also listed on the Current News page. Therefore, the amount of media and news coverage reported in the survey was significantly under-reported. A detailed breakdown of media and news coverage provided on NHDD activities (as taken from survey respondents) can be viewed in the chart below.

- Additional Types of Media and Advertising Used (% Selecting)



\*Please note that the total media and news coverage provided for NHDD activities was significantly under-reported by the survey respondents, as described in the section above.

- Media that Provided News Coverage Event/Activity (% Selecting)



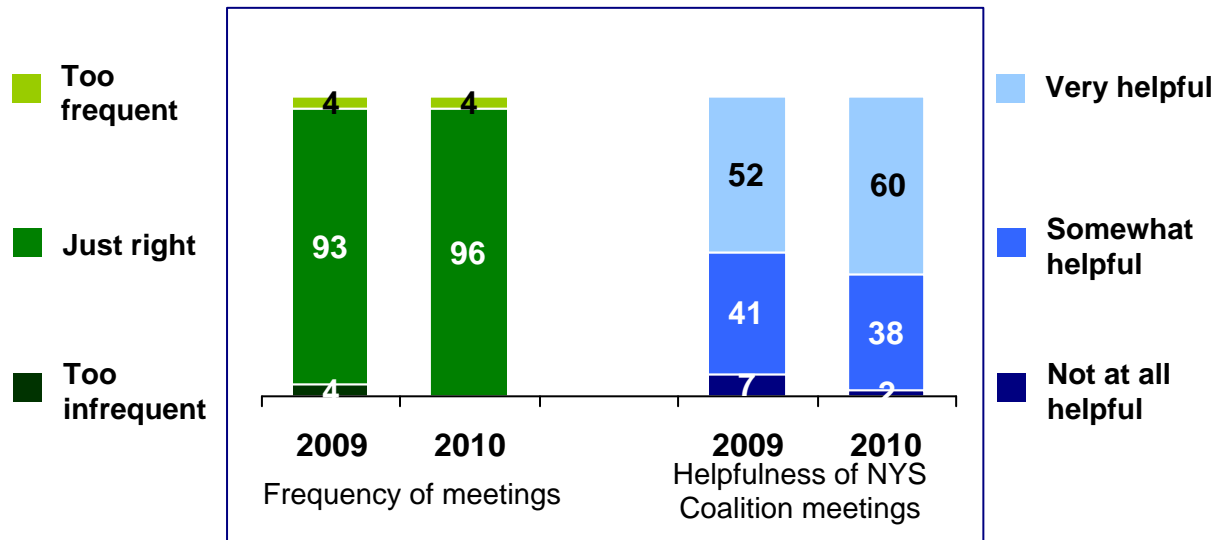
Types of Media that Provided News For Coverage for Event/Activity (% Selecting)

Attribute	2009 %	2010 %
Newspaper	30	40
TV	20	40
Radio	40	30
Magazine	-	-
Web site	10	20
Other	30	20

### Perceptions of NYS Coalition Meetings

Respondents were asked on the survey to describe the frequency and helpfulness of the New York State Coalition Meetings. A more detailed breakdown of attendees responses in 2009 compared to 2010 are displayed in the chart below.

- Frequency and Helpfulness of NYS Coalition Meetings (% Selecting)

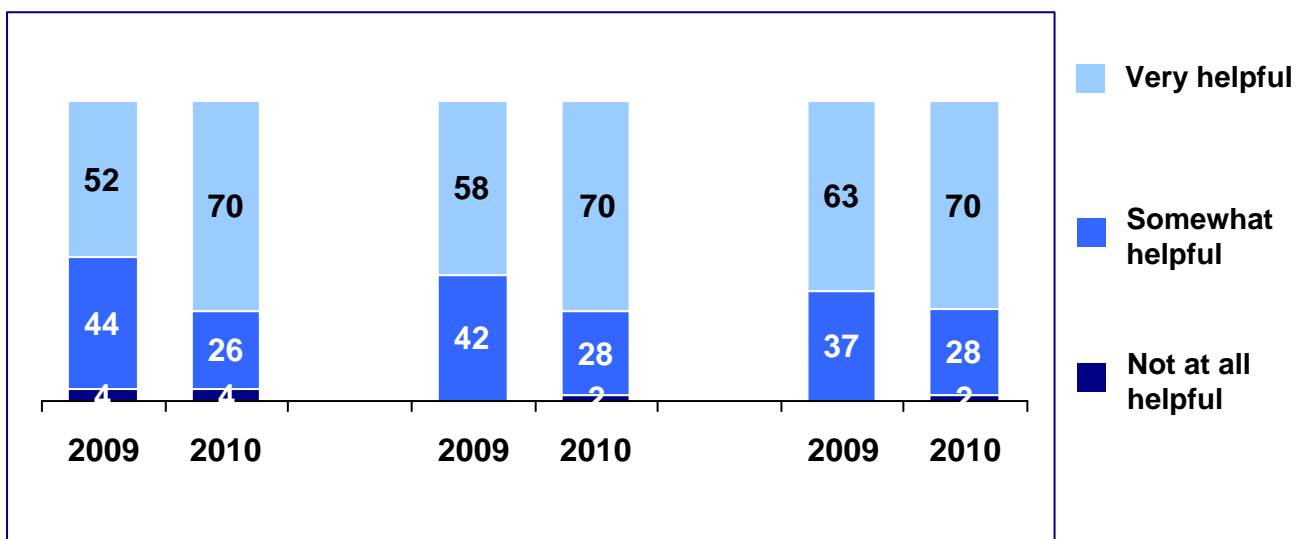


### Utilization of CompassionAndSupport.org Web site for Communication

Question twenty-four on the survey asked respondents to comment on utilization of the CompassionAndSupport.org Web site for:

- Posting meeting announcements and minutes
- Posting NHDD events/activities and event/activity plans
- To list Collaborators

- Utilization of CompassionAndSupport.org as a Communication Tool (% Selecting)



## **Conclusion**

### **Outcome of NHDD 2010**

National Healthcare Decisions Day 2010 in New York State was a great success. As described previously, NHDD activities and events spanned New York State – from Downstate through Upstate and Western New York. The activities described in this report truly only represent a snapshot of everything that took place surrounding NHDD 2010. As NHDD becomes an established event in New York State it is expected that participation and media coverage will only improve.

### **Feedback and Lessons Learned for NHDD 2010 and Beyond**

The success of NHDD 2010 required an extraordinary amount of coordination and planning from individuals across New York State. Some of the most critical elements learned from this experience with NHDD are:

- “By having a greater amount of minority participants In a few years the majority of seniors will be Latinos. I am presently working to improve and expand HOME Health Care to the Latino population. On the same vain we need to support the health aids that work in these homes. The salaries are below the standard. The salary base keeps them at the poverty level.”
- “I picked up several ideas to use with the facilities with which I work. I intend this fall to try to implement some of them. the participants have been very helpful and willing to share ideas which are excellent.”
- “The sharing of ideas, especially what has been successful and the lessons learned”
- “Always open to hearing ideas and efforts of others and also summaries of what’s happening in the legislative arena!!!!”
- “Provided consistent collateral for marketing the 3 day event.”
- “I have found the coalition to be a great group of doers and I look forward to recruiting more people for this very important program.”

### **How Could the NHDD NYS Coalition be Improved?**

- To have at least one representative from each county or area that would participate in the conference calls, activities and events.
- Develop downstate partners; have some conference calls focus on MOLST only since MOLST has not yet been implemented in this area yet.
- A request for more specific action steps for community members
- I think we need more publicity throughout the year. I think we need buy on from the major networks and elder care organizations.

### **NHDD 2009 Events Listing on [CompassionAndSupport.org](http://CompassionAndSupport.org)**

- [Statewide NHDD Events and Activities](#)
- [Regional NHDD Events and Activities](#)
- [Colleges and Universities NHDD Events and Activities](#)
- [Activities Supporting NHDD](#)
- [2009 NHDD Archived](#)