A NATIONAL DIALOGUE

On Health Information Technology and Privacy

October 27th - November 3rd, 2008

patterns digital storytelling disability
disclosure discrimination dna doctors e-prescribing education
education/training of vulnerable populations ehr electronic medical records
electronic prescriptions emergency employment emrs encryption
enforcement eob erroneous error errors exceptions expectation of privacy
family fda feature vectors finance fraud genetic information google docs
government data government roles governmental and corporate intrusion grants
h.r. 6898 health health 2.0 health care is local health care policy
health care records health information exchange
health it adoption health professions health record banks
health records healthcare costs hipaa hipaa privacy rule hippa
identity individual control information information sharing
informed consent insurance insurance company internet banking security
interoperability jaffee v redmond law enforcement legislation legistlation
less effective use of time in practice market solution to healthcare
marketing preferences medical home ehr medical identification bracelet
mental health records mental illness mib
middle road between nationalized health and private insurances
national committee for quality assurance numeric web search objectivity in medicine
online health records online phr open source openness paperwork patient
patient-centered life-cycle value chain model
viders penalties personal responsibility petitions
sts phi phr portability practice silos preferences
rivacy private practice private practice exposures

2009

NATIONAL ACADEMY OF PUBLIC ADMINISTRATION®

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Cover and back cover illustrations are taken from the actual tag cloud for the National Dialogue on Health IT and Privacy. The interactive tag cloud is available at http://www.thenationaldialogue.org/healthit/tags.

A Report by a Panel of the

**NATIONAL ACADEMY OF
PUBLIC ADMINISTRATION**

*For the U.S. Office of Management and Budget, the General Services
Administration, and the Federal Chief Information Officers Council*

February 2009

A National Dialogue on Health Information Technology and Privacy

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FOREWORD

Increasingly, government leaders recognize that solving the complex problems facing America today will require more than simply keeping citizens informed. Meeting challenges like rising health care costs, climate change and energy independence will require a level of collaboration that we have never seen before. Traditionally, government agencies have operated in silos—separated not only from citizens, but from each other, as well. Nevertheless, some have begun to reach across and outside of government to access the collective brainpower of organizations, stakeholders and individuals.

The National Dialogue on Health Information Technology and Privacy is one such initiative. It was conceived of by leaders in government seeking to demonstrate that it is not only possible, but beneficial and economical, to engage openly and broadly on an issue that is both national in scope and deeply relevant to the everyday lives of citizens. The results of this first-of-its-kind online event are captured in this report, together with important lessons learned along the way.

It is our hope that this report serves as a call to action. On his first full day in office, President Obama put government on notice that this new, more collaborative model can no longer be confined to the efforts of early adopters. He called upon every executive department and agency to "harness new technology" and make government "transparent, participatory, and collaborative."

Government is quickly transitioning to a new generation of managers and leaders, for whom online collaboration is not a new frontier but a fact of everyday life. We owe it to them—and the citizens we serve—to recognize and embrace the myriad tools available to fulfill the promise of good government in the 21st Century.

Jennifer L. Dorn
President and Chief Executive Officer

ACKNOWLEDGEMENTS

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APPENDICES

ACRONYMS

Academy	National Academy of Public Administration
CDC	Centers for Disease Control and Prevention
CIOC	Federal Chief Information Officers Council
Dialogue	The National Dialogue on Health Information Technology and Privacy
DoJ	U.S. Department of Justice
eGov	E-Government, or Electronic Government
EHR	Electronic Health Record
EMR	Electronic Medical Record
EPA	U.S. Environmental Protection Agency
E-Prescribing	Electronic Prescribing
FOSS	Free and Open Source Software
GSA	U.S. General Services Administration
HIT	Health Information Technology
HMO	Health Maintenance Organization
IT	Information Technology
NIEM	National Information Exchange Model
OMB	Office of Management and Budget
ONC	Office of the National Coordinator for Health Information Technology
PHR	Personal Health Record
VA	U.S. Department of Veterans Affairs
VistA	Veterans Health Information Systems and Technology Architecture

Web 2.0   Web-based, interactive tools and media in which:

- Content is oriented primarily to create a rich and engaging user experience;
- Users are an integral part of the value that is added to the content and data online; and
- Users' interactions with the information (both collectively and individually) can significantly alter the experience of subsequent users.[*]

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[*] Definition courtesy of U.S. Environmental Protection Agency.

EXECUTIVE SUMMARY

SUMMARY OF FINDINGS

In September 2008, the U.S. Office of Management and Budget (OMB), in conjunction with the General Services Administration (GSA) and the Federal Chief Information Officers Council (CIOC), contracted with the National Academy of Public Administration (the Academy) to pilot an interactive, web-based discussion platform—labeled a "National Dialogue"—as a means to engage members of the public on relevant issues. This discussion, which launched on October 27, 2008 and continued through November 3, 2008, focused on answering the question: "How should we expand the use of information technology and protect personal privacy to improve health care?"

There are many reasons to pilot the use of "Web 2.0"[1] approaches to engaging the public in dialogue. We were driven by two:

1. ***Progress on the issue.*** Improved health outcomes require the application of information technology to health care, which in turn raises significant privacy concerns. Unfortunately, progress in reaching consensus on these issues has been hampered by a debate that focuses on areas of disagreement rather than seeking to find common ground. We believed that a collaborative, Web 2.0 approach that engaged a larger and more diverse community would increase the potential for new and innovative ideas to emerge, and could potentially foster broader consensus on this issue.

2. ***A model for others.*** Nothing speeds adoption like success. An initiative that both demonstrated value (i.e. yielded progress on the issue of HIT and privacy) and provided proven tools (i.e. a model for hosting future public and stakeholder dialogues) would encourage others in government to engage in similar activity.

The Dialogue was powered by a unique platform that allowed users to submit ideas, refine them through discussion and vote on the submissions they found most appealing. These simple features ensured that, as more and more users join the conversation, the best ideas—as identified by the community—rose to the top.

In designing this Dialogue, we sought to achieve two specific goals. First, to engage stakeholders and citizens in suggesting, discussing, and prioritizing innovative ideas; and second, to identify important concerns, guiding principles, and personal stories concerning health care information technology and privacy.

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[1] The U.S. EPA has developed one of the best definitions of Web 2.0 we have seen to date. They define Web 2.0 as web-based, interactive tools and media in which:
- Content is oriented primarily to create a rich and engaging user experience;
- Users are an integral part of the value that is added to the content and data online; and
- Users' interactions with the information (both collectively and individually) can significantly alter the experience of subsequent users.

During the weeklong discussion, the website had more than 4,000 visits by more than 2,800 unique visitors, generating hundreds of ideas and comments.[2] Every state and territory as well as 80 foreign countries were represented. When the online dialogue concluded, a Panel of Fellows of the National Academy analyzed the ideas and assessed the relative importance to the community based on the number and magnitude of ratings and comments each received, as well as their own deep knowledge and expertise.[3]

The analysis conducted by Panel of Fellows yielded three key conclusions about the substance of the discussion:[4]

- ***Policymakers must help the public reconcile personal health care concerns with other benefits of health IT.*** The National Dialogue provided important insight into how ordinary citizens who are not experts engage with issues of health IT and privacy. Participants largely envisioned a model of health care that placed their personal health care at the center, with "other uses" of health information (such as public health, research and health care practitioner training) divorced from personal health outcomes. The Panel observes that the public needs to be made aware that access to patient care data for research, practitioner training, and public health purposes is essential for the continuous process and quality improvement that will redound to the benefit of all patients and will enable the reform of the health care system.

- ***Further exploration of key themes is needed.*** The Panel identified three overall themes that characterized much of the discussion on the Dialogue site: Health and Privacy Trade-Offs, Health Information Technology, and Health IT Best Practices. Because these themes were surfaced but not fully explored during the week of the Dialogue, the Panel recommends in this report that policymakers continue intensive public engagement on these specific aspects of health IT and privacy, and that these efforts build upon the insights gained during this initial National Dialogue.

- ***A set of principles informed by public engagement should be a starting point for crafting policy.*** Recognizing the importance of these governance and health care issues, the Panel augmented the National Dialogue through consultation with experts. Based on both of these sources, the Panel has proposed an initial set of principles to guide health information use while appropriately safeguarding privacy. The Panel believes that it identified potential and meaningful common ground. Even though these principles represent starting points rather than well-defined conclusions, they may constructively advance the policy debate concerning health information technology and privacy.

The Panel also examined the National Dialogue as a methodology for public engagement, and concluded:

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[2] Submissions can be accessed at: http://www.thenationaldialogue.org/healthit.
[3] A listing of Panel members and their biographies can be found in Appendix A.
[4] It is important to note that this initiative was not intended to solicit nor does it provide a representative sample of American citizens' views on Health IT and Privacy.

- ***Public engagement is critical to successful policymaking.*** Initiatives like the National Dialogue have enormous practical potential to introduce the public's concerns and priorities into government deliberations. Enhanced public engagement is increasingly viewed as a prerequisite for durable, credible policy positions that reflect both layperson and expert opinions. Although limited in scope, this pilot demonstrated that, with refinement, collaborative platforms can effectively engage an interested community of participants and focus them on a particular issue.

- ***This Dialogue revealed key insights about the debate over health IT and privacy.*** This initiative demonstrated significant potential for engaging "we the people" in the process of governance. It tapped the Internet's capacity to bring together a wide range of stakeholders and citizens whose views were not shaped through an adversarial process. In doing so, the Dialogue revealed substantial agreement on core values, common areas of concern, and even strategies for future public engagement that otherwise might not have surfaced. In sum, the method works.

- ***Future efforts can and should build upon this pilot.*** The feasibility and strength of the online dialogue methodology have been demonstrated. Further, the Panel is confident that the results of this effort represent an appropriate basis for further exploration. The critical next step requires expanding participation to a larger and more representative sample of the general population, which is an achievable goal. The technology platform for this Dialogue can support what otherwise might be logistically or fiscally infeasible. However, there is a learning curve to this technique, and further application is likely to yield even more effective ways to expose those in government to valuable ideas and priorities of those outside government.

CONSOLIDATED LIST OF RECOMMENDATIONS

The Panel's formal recommendations are listed below for easy reference. Chapter 2 provides a comprehensive discussion of the Panel's findings and rationale.

Recommendation #1: The Panel recommends that the Administration make a public commitment to further exploration of methods of public engagement, such as the National Dialogue, that give participants the opportunity to share their ideas; provide clear choices regarding public policy options; focus on building durable consensus on national issues; and are informed by the application of independent, neutral expertise to the ideas, concerns, and priorities that emanate from such engagements.

Recommendation #2: The Panel recommends that the Administration continue the conversation begun in this National Dialogue with enhanced efforts to engage a broad stakeholder community around issues of health IT, privacy, and ultimately, the overall delivery and quality of health care in this country.

Recommendation #3: The Panel recommends that efforts to refine the National Dialogue process focus on improvements in the following areas: timing and logistics; broader and more successful outreach; implementing a multi-stage process that yields more concrete feedback; more effective mechanisms for prioritizing and ranking the content generated by participants; enhanced collection and analysis of demographic data about participants; and the addition of in-person interactions to ensure representation of the views of people who lack ready access to the Internet.

Recommendation #4: The Panel recommends that future efforts to engage the public on issues of health IT and privacy proceed from the objective of helping participants understand the connections between a person-centered view of health care information and the benefits of using personal heath care information for appropriate broader purposes.

Recommendation #5: The Panel recommends that future efforts to engage the public on the issue of health information technology and privacy should be directed towards finding a synthesis of concerns about information use and privacy, rather than let the debate be focused on and governed by the extreme positions on these issues.

Recommendation #6: The Panel recommends that future efforts to engage the public on the issue of health information technology and privacy should place an emphasis on quantifying and clarifying the potential cost reduction and quality enhancement benefits of expanded use of health IT, and the effect that privacy concerns play in health IT adoption. Efforts should also include a component that makes the analysis and the raw data underlying the empirical case for various aspects of health care reform directly available to the public.

PROJECT OVERVIEW

THE NATIONAL DIALOGUE CONCEPT

Since the passage of the E-Government Act of 2002, the federal government has made progress in becoming a more efficient, citizen-centered government. However, new collaborative tools enable government to more directly engage their stakeholders—and the public at large—in setting the national policies and priorities. Many countries, including Singapore, the United Kingdom, New Zealand and Canada have launched initiatives aimed at increasing government-citizen interaction.

This National Dialogue pilot represents an effort by government to look beyond its own walls to discover key concerns and surface innovative solutions to our most critical national challenges. This approach brings new voices into the debate and fosters a more collaborative approach.

Traditional methods of public policy formulation have required policymakers to select in advance the voices that will have a role in influencing their actions. As a result, our national debates have generally been shaped by a fairly limited number of participants who approach issues from opposite and often adversarial viewpoints. Often, the goal is to create and "win" policy conflict rather than working towards consensus.

The National Dialogue takes a different approach. It is similar to other efforts that solicit feedback from citizens but it goes further, both in the sheer number and diversity of views it can accommodate and through features that enable the aggregation, organization, and prioritization of vast amounts of input. The Dialogue was powered by a unique platform that allowed users to submit ideas, refine them through discussion, and vote on the submissions they found most appealing. These simple features ensure that, as more and more users join the conversation, the best ideas—as identified by the community—rise to the top. This provides the recipient with rich and potentially actionable data that reflects the concerns and priorities of those participating.

There are several important caveats to note:

- This first National Dialogue was designed as a pilot initiative to provide a proof of concept, and therefore provides a view of only a segment of the issues and participants who might be involved in a larger effort.
- Because this National Dialogue was an online conversation, it does not contain the views of those who cannot or do not engage in online activity.
- This pilot emphasized the generation of new and interesting ideas and perspectives rather than focusing on methods of achieving consensus.
- The analysis in this report is a product not only of the Dialogue process but of thorough analysis by a Panel of knowledgeable and experienced Fellows of the National Academy.
- As a pilot, this National Dialogue yielded several critical lessons and improvements for engineering more effective rating and sorting mechanisms on future projects.

Taking into account its inherent limitations, the Panel believes strongly that the National Dialogue on Health Information Technology and Privacy provided a persuasive pilot of concept for engaging those outside of government in the process of governance, and proved the value and viability of further use of such methodologies in the future.

SELECTING A TOPIC FOR DISCUSSION

In seeking to engage citizens and stakeholders in an online collaborative discussion, it was important to choose an issue that was national in scope and relevant to people's everyday lives.

While there is a broad spectrum of opinion on how to solve America's health care crisis, there is general agreement that any solution will require a government role in the efficient and effective management and protection of citizens' personal health information. The American health care system is on a road to transforming how it stores, shares, and uses health information. Thanks to the digital revolution that has occurred in recent years, health information technology offers the possibility of both reducing health care costs and preventing medical errors while simultaneously improving health care and health status through timely access to individual patient information and clinical guidelines.

At the same time, our ability to capture and use information efficiently while also effectively safeguarding citizens' privacy is the subject of much debate. It raises significant questions and concerns about how our personal information should be used, shared, and protected. The purpose of the National Dialogue pilot was to engage a community in finding common ground on how to take advantage of these benefits, reduce any risks, and build solutions.

Government has also made substantial progress in becoming a modern and effective policymaker in this arena: The Office of the National Coordinator for Health Information Technology, Consolidated Health Informatics E-Government initiative and the Federal Health Architecture Line of Business are laying the foundation for a comprehensive health information management framework. The U.S. Department of Veterans' Affairs has launched a number of innovative health IT management initiatives. A host of substantial reform proposals are currently before Congress. By engaging citizens in a dialogue focused specifically on health care IT and privacy, we are attempting to build on this legacy by pioneering an innovative, engagement-oriented approach to these issues.

For all of these reasons, the primary question for the National Dialogue was: "How should we expand the use of information technology and protect personal privacy to improve health care?"

LESSONS LEARNED

While this National Dialogue pilot provided valuable feedback from participants regarding concerns and priorities relative to health IT and privacy, its primary value is a test of the viability of using the Internet to engage stakeholders and citizens in the policymaking process. The Panel believes strongly that by exploring processes such as the one tested in the National Dialogue pilot, government will continue to find new and innovative ways to include stakeholders, experts, and citizens in the process of governance.

The Panel has examined this National Dialogue for lessons learned so we may continue to refine the process for future efforts. In addition to overall lessons, the Panel has identified important procedural outcomes and insights in three areas: Content, Outreach, and Technology. These three areas represent the crucial components of this National Dialogue pilot: informing participants about the various schools of thought around a specific issue; providing the opportunity for people to make their voices heard; and implementing a technology platform capable of aggregating participants' input into priorities and themes that potentially build toward consensus positions.

The following are some overarching lessons gained from this National Dialogue pilot.

People Are Willing (Even Eager) To Engage—perhaps the most important lesson to be learned from the National Dialogue pilot is that, when asked and presented with a clear value exchange, citizens and stakeholders are eager to engage in the process of governance. The Dialogue had a very meager advertising budget (<$10,000) and took place the week before a major national election. Despite this, the Dialogue garnered 4,413 visits from 2,835 unique visitors, with 420 of those—nearly 15%—going on to create an account on the Dialogue site. The Dialogue produced not only a substantial number of ideas, but also fostered discussions of those ideas in which participants responded directly to each others' arguments. This demonstrates persuasively the potential value of bringing together a wide range of participants and allowing them not only to respond to a single point of contact, i.e. directly to leaders in government, but to interact with and respond to each other.

Civic Engagement Is a Starting Point—using this type of citizen feedback to effectively guide policy requires a clear-eyed view of what purposes such public engagements do and do not serve. While tools like the National Dialogue are useful for generating innovative ideas and uncovering insights into the concerns and priorities of participants, they are not representative of "the people" as a whole. The Panel believes strongly that this National Dialogue did uncover important insight into the shape of debate on health IT and privacy. The Panel also believes that building on this initiative would continue to provide policymakers with valuable insights and interested citizens with a needed forum to express and debate their views. However, no civic engagement used in isolation, online or otherwise, can deduce consensus where none existed previously. Ultimately, initiatives like the National Dialogue must mark the beginning, rather than the end, of public debate on any given issue.

Timing Is Important—the timing of the National Dialogue presented a unique challenge that, in the view of the Panel, kept this effort from reaching its full potential. In order to better demonstrate the ability of leaders to quickly solicit and analyze large amounts of feedback, and to prove the viability of such methods in advance of a presidential transition, the National Academy and its partners built and ran the National Dialogue pilot, from start to finish, in a time span of about six weeks, and conducted the Dialogue itself over the course of one week. While this quick turnaround limited the extent of the participation, it also demonstrated that even efforts as brief as the pilot can create real value that could not be achieved without the use of the online dialogue method.

The use of this type of method should, although valuable, be distinguished from more scientific surveys of public opinion. It is too soon, in the judgment of the Panel, to claim that the views of the public or any significant subset of it can be ascertained reliably using this method. That possibility would need to be tested in subsequent projects that would include breadth of participation as a primary objective.

CONTENT

Decisions about the content and design of a public dialogue play a critical role in shaping the outcomes of the process and the experience of participants. There are three core elements of content and design:

1. The format and structure of the website, which impact content and design;
2. The substantive background text provided to participants to ensure a basic level of understanding of the Dialogue's subject matter; and
3. The discussion questions posed to participants to guide discussions.

These elements were in turn designed with three goals in mind:

- *Credibility*—did these elements help to establish the credibility of the National Discussion with participants, stakeholders and decision makers?
- *Informed Participation*—did these elements help to ensure that participation was grounded in key facts about the policy issue?
- *Objectivity*—did these elements help to guide the discussion in a useful and productive manner without biasing the discussion?

Ultimately, we have been unable to determine the extent to which the content provided on the site had any effect on the resulting discussion. Metrics indicate that the pages within the "info" subdirectory of the site, which housed all informative and educational material, received only 1,714 page views, or 5.36% of the site's total traffic. Other qualitative findings include:

- *Limited Citation of Materials*—direct reference to the background content or discussion questions in the posted comments was limited. Possible explanations include: participants did not read the questions or background content; participants read but did not find useful the questions or background content (possibly because many participants were knowledgeable on the topic); or participants were influenced by background content but did not reflect this in their comments.
- *Detailed Discussion*—whether or not users referred to the content and questions, the Dialogue did feature detailed discussions and comments, which included the citation of facts about the topic matter and use of expert knowledge. Participants did respond to one another's ideas, often providing factual justifications for their arguments.
- *No Challenge to Content*—participants in the National Dialogue provided little to no dispute of the information that was given to them. This may be because the information was factually correct and balanced, because the information was ignored, or both. Given the polarizing nature of the issue, the lack of dispute to the content has been taken as a positive indicator.

- ***Responses to Participant Ideas***—in keeping with the format of the Dialogue, most comments and ideas responded to other participant comments and ideas. Many comments addressed specific issues that were raised by discussion prompts. It is unclear whether they would have been raised if the discussion prompts had not been present.

The decisions made regarding structure and format of the National Dialogue provide insight into the role that pre-developed content or discussion questions can play in the process:

User-Generated Content

The National Dialogue used a format that was based primarily on user-generated content; the core organizing structure of the Dialogue was the set of ideas that users generated themselves. Background content and suggested discussion questions were provided, but they were positioned to the side and on linked pages. While this content was readily accessible to users, it was not featured as prominently as the opportunities for user interaction and submissions. Featured more prominently were the ideas that participants created, which then solicited ratings and responses. For these reasons, users may have simply begun to interact without taking the time to read the prepared content.

The lesson is that strategic choices around the structure and format of the website play a substantial role in how educational content is used. If it is important that specific questions be addressed or policy options be selected, then it is important to design a platform that gives visual and interactive attention to those questions or options. If user content shapes the discussion, as was the case in this engagement, then that will lead to a different design for the discussion platform.

Central Question with Discussion Prompts

The framework for the discussion was set on the homepage of the National Dialogue site, with a single proposition statement that set out what the Dialogue was about: "How should we expand the use of information technology and protect personal privacy to improve health care?" Discussion prompts were rotated on the side of the home page, with links to additional questions. The discussion prompt questions were open-ended and did not have a mechanism that compelled participants to respond specifically to the discussion question.

Although the content guiding the discussion provided background information on a number of key issues, it was not explicit in laying out the various choices that participants might have to make in forming opinions on these issues. As a result, much of the feedback received from Dialogue participants was aimed at generating new ideas rather than setting priorities within the bounds of current debate.[5] Framing of discussion questions is one area in which time constraints impacted the project team's ability to consult outside experts to formulate concise, targeted questions that would elicit more focused responses.

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[5] For more on the impact of this strategic choice, see "Technology Platform and User Experience" in Chapter 3.

The lesson is that strategic choices regarding structure and format has a substantial impact on how and whether content plays a role. If it is important that specific questions be addressed or preferences in policy options be elicited, then the platform must be designed around those questions or options. If user content should shape the discussion, with background information playing a guiding but not limiting role, then that will lead to a less structured but more innovation-focused discussion.

Consider the Audience

The content developed for the National Dialogue provided introductory information, intended for those who knew little about the topic. Yet while the Dialogue was open to anyone, recruitment and outreach efforts were aimed chiefly at established stakeholder communities, members of which likely to have well-formed views on these issues. For this audience, the value of the Dialogue was not in informing them on issues related to Health IT and Privacy, but rather in the forum it provided that otherwise would not have been available. The lesson here is basic—that educational efforts are less important when reaching out to audiences well informed on the subject of discussion.

Content and Design Development

Content and discussion questions were developed by the project team based on a survey of leading research. Draft materials were validated and refined by an Advisory Committee, composed of subject matter experts who were excluded from participation on the project Panel.[6] Although the Advisory Committee lent deep expertise to the review process, the content was not developed by experts and was not framed to provide specific choices to participants. It was in this manner that the Dialogue maintained balance and credibility. The lesson is that special attention should be paid to securing a diverse enough group of advisors who are willing to spend sufficient time providing feedback on content and discussion materials.

While there is substantial room for further improvement in the process for both content development and alignment with other elements of the effort, it is clear that the content developed for this National Dialogue pilot was an important asset in lending credibility to the Dialogue, as well as ensuring that participants began on a level playing field of information.

BUILDING THE COMMUNITY

The outreach campaign for the National Dialogue pilot sought to gain participation by leveraging pre-existing relationships and social networks. Ultimately, nearly 800 groups and individuals were contacted regarding this effort, many of whom disseminated information about the Dialogue through distribution lists or networks of hundreds or thousands of members. The following were critical elements for the Dialogue:

- *Quality and Quantity of Participation*—due to factors including timing, advertising budget, and the specificity of the topic, this effort targeted established stakeholder groups

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[6] For a listing of Panel members and their biographies, see Appendix A.

rather than a broad segment of the population. This approach led to participation from educated professionals, resulting in a high level of content quality. However, amount of time spent on the site may have been negatively impacted by competing demands on the time of audience members.

- *Participation Requirements*—outreach to stakeholders included specific guidance on the amount of time needed to participate in the Dialogue. The recommended time commitment was 30 minutes, three times during the eight-day Dialogue. This was likely sufficient at the front end of the Dialogue, when participants would have had only a few posts to peruse, but insufficient towards the end of the project, when the site contained over 150 posts and hundreds of comments. Additionally, well-thought out responses may have required more time than anticipated.

- *Early Participation*—the website launched on October 27th. To ensure early visitors were not faced with a daunting empty page, the nearly 100 people who pre-registered for the site were invited via email to post comments they had sent in prior to the Dialogue. A number of thought leaders were invited to do the same.

- *How Does This Work*—the National Dialogue featured leading edge, user driven features, which despite providing robust functionality to some users, may have left other users behind. An optional tutorial was available and may have required greater promotion to users to ensure all participants were able to navigate all features.

Other important lessons on building the community for the National Dialogue have to do with the manner in which outreach was conducted:

- *Online Projects Require Online Outreach*—face to face and phone outreach initially played an important role in soliciting the support of key opinion leaders. However, most project outreach relied on online tools that enabled potential users to simply click on a link to get more information, rather than having to remember to visit the website after learning about it in orally.

- *Referrals are Key*—personal recommendations and referrals are a critical to recruiting participants. Contacts were asked to provide a list of others who might also be interest in hearing about the effort. Thus, e-mail or phone outreach to new contact began with, "person X recommended I contact you about this project." Consistently, this approach yielded better outcomes than "cold" outreach.

- *Have a Clear "Ask"*—potential participants were asked to do three simple and related tasks: (1) sign up, (2) book time on their calendar to participate, and (3) forward an e-mail message to their colleagues and list serves.

- *Make it Easy*—standard outreach e-mail and call scripts were crafted for use by the outreach team, and applied hundreds of times, resulting in many successful person to person introductions about this pilot project. Tools such as e-mails, newsletter articles, blog posts, and web banners were provided to support participant promotion.

Additionally, presence on social networking sites such as Twitter, Facebook and chat forums allowed participants to invite their networks to visit the project website through multiple channels.

- ***Web Presence is Essential to Legitimacy***—the National Dialogue began its outreach as early as possible, even before a holding page was online. Once this "splash page" was available, outreach team members had increased success in developing support and commitments to participate. The splash page consisted of simple information about the project, a sign up form and a field to provide initial comments.

- ***Tracking helps Achieve Diverse Representation***—the outreach team methodically monitored the list of outreach contacts and participant sign ups according to key demographic targets. When there was an imbalance of sector, geography or other important indicators, the outreach strategy was adjusted to correct the imbalance.

- ***Stay in Touch***—e-mail updates were sent regularly to participants and key supporters during the project. These updates highlighted active topics, encouraged users to rank ideas and introduced a new video developed for the project. These e-mails help drive repeat visits to the National Dialogue.

TECHNOLOGY PLATFORM & USER EXPERIENCE

The Panel sees the technology platform that powered the Dialogue and the environment that it created for participants, as the most critical determinant of user participation and their contributions.

Types of Public Engagement

The strategic alignment between the desired outputs of an event like the National Dialogue, and the way in which the content and platform are structured is of the utmost importance. This is fundamental to the distinction between four related but ultimately very different types of public deliberation formats:

- Idea Generation and Refinement;
- Prioritization;
- Choicemaking; and
- Consensus-Building.

The model that powered the National Dialogue pilot was idea generation. In this format, users are presented with an unstructured participation mechanism: the submission of an idea, and the ability to discuss and rate the ideas of others. This pilot provided a number of useful mechanisms for "sharpening" this feedback, such as assigning it to categories or explaining its importance in terms of the overall debate. However, it did not require participants to locate their preferences along a spectrum of possibilities. Platforms that use this model tend to be most productive in generating innovative ideas, but do not ultimately present policymakers with a clear sense of participant preferences relative to various concrete questions.

Choicemaking and prioritization mechanisms, by contrast, are most appropriate when policymakers are seeking to understand participant preferences within a constrained universe of options, through asking them either to choose between ends of a continuum or prioritize various options. For example, citizens might be asked, "Should we spend more or less on social programs?" or "Which is more important, lowering tax rates or balancing the federal budget?" Such engagements are more likely to produce an explicit set of preferences, but are less likely to produce new and innovative ideas, since they occur within the bounds of pre-defined questions and choices. This type of mechanism can also be used following an initial "Idea Generation and Refinement" phase, where the prioritization and choicemaking is performed on a pool of ideas generated and refined in the first stage.

Consensus-Building is a third format, in which the goal is to move participants towards either total agreement on, or having no significant objection to, a given position. This may incorporate many elements of Prioritization and Choicemaking, such as votes toward a majority or votes on prioritization, but nearly always requires work beyond voting or prioritization.

The National Dialogue effort was modeled after efforts in both government (e.g., the Transportation Security Administration's IdeaFactory[7], a module for harnessing ideas from front-line employees) and the private sector (e.g., Starbucks' MyStarbucksIdea[8], which solicits innovations from customers) that follow the Idea Generation model. While the National Dialogue pilot did generate a number of innovative ideas, it was not designed to nor did it produce a clear set of preferences on the part of participants. It also did not, nor was it designed to produce a policy debate amongst subject matter experts.

A Choicemaking format produces results that are only valid if the group of participants reflects the preferences of the population as a whole. That was not the case with this initiative. Moreover, while the debate did not correspond to traditional debates on the issue, it did yield helpful data that reveals how citizens and stakeholders outside of government see the debate and the issues they feel are most at stake. Exposing this disconnect is in itself a valuable result. Another lesson from this National Dialogue is the importance of aligning the design of the user experience with the type of information that one hopes to obtain by deploying mechanisms for public deliberation, while balancing the trade-offs inherent in choosing any particular model.

A Multi-Stage Process

This finding pertains to a kind of inertia that persisted throughout the week of the Dialogue. In general, ideas submitted early in the week attracted the most discussion, as well as more (if not higher) ratings. Elements of the site attempted to counteract this by enabling users to sort their view to show more recent submissions first, for example. This was helpful but did not eliminate the "early submission bias".

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[7] Bain, Ben. "4 studies in collaboration—Case 2: TSA's IdeaFactory." Federal Computer Week. <http://fcw.com/Articles/2008/02/29/4-studies-in-collaboration-151-Case-2-TSA146s-IdeaFactory.aspx> March 3, 2008.

[8] Available at http://www.mystarbucksidea.com.

One option for future Dialogues would be to deploy platforms that allow separate stages for the submission, refinement, and rating of ideas. In this Dialogue, such a platform was impractical because of the one-week timeframe allotted to the effort. Instead a platform was deployed that allowed simultaneous submission, discussion, and rating of user submissions. A multi-tiered process which gives participants separate periods for submitting ideas, refining them through discussion and collaborative editing, and finally rating and prioritizing them, should produce a more distilled, actionable set of ideas within the context of an Idea Generation model.

A model such as this would require an extended timeframe and a high level of involvement from participants, which could also limit participation to those who already have staked out a firm position in the debate. In other words, such a process might gain a more productive deliberation at the expense of bringing more innovative, original perspectives into the discussion. Nonetheless, the Panel feels that future efforts in this vein should seriously explore the prospects for a multi-stage process.

Refined Voting Mechanisms

Giving participants the ability to vote on ideas is core to the National Dialogue. Besides soliciting large amounts of feedback, it aggregates data and highlights ideas that resonate most powerfully with the overall community. However, in the context of Dialogue, further refinement of the voting mechanism might have yielded a clearer picture of how the community viewed certain ideas.

In the system that was deployed, participants had the opportunity to rate ideas on a scale of 1 to 5, with 5 representing the most positive reaction. Overall ratings assigned to ideas represented an average of the ratings they received. As a result, an idea that had been rated as a 5 by one person would have a higher overall rating than a different idea that had been rated a 5 by two people, but rated a 2 by 20 people.

Particularly given the "early submission bias" discussed earlier, this produced some idea ratings that seemed at odds with the discussion that evolved over the weeklong Dialogue. This rating system also ultimately produced some misalignment with the input categories given to participants; it is unclear, for example, what it would mean if a user's personal story was given a low rating.

The success of any idea rating system is ultimately dependent on the number of votes and the representative participation in the rating activity. Nevertheless, there are several ways to enhance the process for rating ideas. One possibility is replacing the rating system with the ability to promote or demote an idea. Such a mechanism powers the popular social bookmarking site Digg.com. This type of platform could conceivably produce not only ratings, but perhaps a rough aggregate prioritization of ideas. Another option is to use an alternative scoring system that provides a composite score based on both the aggregate ratings and the number of votes an idea received.

The Panel recommends that the rating system be refined in future Dialogues to that it accurately captures community preferences and is in alignment with the type of feedback being solicited.

FINDINGS AND RECOMMENDATIONS

FINDINGS

The National Dialogue on Health Information Technology & Privacy should be seen as a pilot project using modern tools to pioneer new methods of involving people outside of government in the process of governance. Particularly because this National Dialogue pilot was one of the first of its kind, assessing outcomes requires consideration of several questions:

- Was the effort conducted properly and in a way that solicited genuine participation?
- Was the participation itself substantive and relevant to the subject matter at issue?
- Can valuable insights or lessons learned be gained from the effort?
- Does the effort prove the potential of further exploration and refinement of the concept?

Having evaluated the effort with respect to each of these dimensions, the Panel has come to the following conclusions:

Was the effort conducted properly and in a way that solicited genuine participation?

While some ordinary citizens were able and invited to participate in this National Dialogue, the conversation was held chiefly among experts and stakeholders, i.e., people with direct associations to groups with a defined stance on one or more aspects of the issue being discussed. So while this report repeatedly refers to "citizens and stakeholders" as the participants in the effort, and indeed this description is accurate, it is not accurate to construe that there was broad and substantial public participation or that most participants came into the discussion without preexisting opinions or the desire to advance or rebut specific arguments.

With that caveat, the Panel concludes that:

- This National Dialogue pilot did succeed in establishing an online platform in which interested parties from both within and outside government could express their opinions on important aspects of health IT and privacy, and within certain limitations, indicate which themes and ideas they found to be most deserving of further discussion; and

- Those who participated in the National Dialogue pilot overwhelmingly did so in a way that contributed productively both to the success of the initiative in bringing together a wide spectrum of opinion, and to the goal of making their viewpoints known to policymakers in government.

Was the participation itself substantive and relevant to the subject matter at issue?

It is important to note that participants bring to such discussions their own ideas about what is relevant to the issue. For participants, the motivation for engaging in such an effort is often to tell policymakers what they consider important, so that policies ultimately reflect their priorities and concerns.

With regard to the issue of relevance, many of the submissions received over the course of the Dialogue would not be perceived as meaningful in the context of debates about health IT and privacy that are occurring among policy experts, but were nonetheless relevant to related issues or to the lives and experiences of those submitting them. The open format for participation encouraged responses that were "self-centric"; participants tended to describe how they would like to personally experience or change part of a system, rather than a holistic vision for a system of managing health information. These personal stories and viewpoints, while not necessarily aimed at staking out a clear position along the spectrum of debate, are nonetheless compelling and important. They can help policymakers understand where to look for patterns, and surface important "ground truths" that might otherwise be overlooked. Eliciting these stories and viewpoints should be one of the goals of broader public engagement. Moreover, the asynchronous nature of platforms like the National Dialogue makes it possible for those stories to be heard and mined for insight, without impeding other policy discussions.

This assessment of relevance also bears on the question of substantiveness. The National Dialogue pilot was notable more for the breadth of participation than for its depth. Although some discussion topics received fairly substantive treatment, the majority of submissions were not characterized by depth and complexity. This is likely a function of the limited duration of the dialogue, but it also points to the need to further refine the way in which conversation is guided in this type of public deliberation.

Overall, the Panel concludes that:

- Participant input in the National Dialogue, while not resulting in a discussion of the depth and breadth comparable to those taking place among expert policymakers, did cover a broad range of subject matter and provide useful and compelling stories and discussions; and

- Participant input in the National Dialogue touched on some of the contours of the policy debate about this issue as commonly understood by experts, and elicited useful content that accurately describes the relevant experiences and desires of those who participated.

Can valuable insights or lessons learned be gained from the effort?

Executing this National Dialogue pilot has yielded a number of valuable lessons in the areas that are critical to successful online public engagement, including: creating content that educates participants about the issue and its importance; making potential participants aware of the opportunity to submit feedback and have it be received by policymakers; and deploying a platform that effectively stores and aggregates feedback in a way that makes it comprehensible and potentially actionable in a policy setting.

Accordingly, the Panel concludes that:

- The National Dialogue pilot yielded numerous valuable insights and lessons that should be applied to future efforts, and if so applied, will likely result in the development of even more effective platforms for conducting future public deliberations in an online format.

Does the effort prove the potential of further exploration and refinement of the concept?

The answer to this question is unequivocally yes. The Panel applauds the sponsors of this initiative for proactively exploring new ways to bring government more in touch with the ideas and priorities of those it serves, and considers this National Dialogue pilot a strong first step toward such a process.

While different choices and constraints would undoubtedly have provided different outcomes, the Panel concludes that:

- This effort clearly demonstrated that engaging "we the people" in the process of governance, by tapping the Internet's capacity to bring together networks of people that transcend geography, hierarchy and established opinion, is both possible and useful; and

- There is support, at least within some stakeholder communities, for members of the public to play an enhanced role in shaping the ideas and priorities that guide national policy.

RECOMMENDATIONS

In analyzing the substantive outputs of the Dialogue, the Panel attempted to answer three key questions[9]:

- What were the most important themes and ideas to emerge from the discussion?
- How do those themes correspond to the current state of debate on this issue, and in what context are they relevant to and useful for that debate?
- How can the answers to these questions best inform future efforts to use collaborative technologies for civic engagement?

In answering these questions, the Panel begins with a few overarching observations.

Furthering the Goal of a "Transparent, Connected Democracy"

Initiatives like the National Dialogue are directly aligned with the explicit commitment of President Obama to "create a transparent and connected democracy"[10] by engaging the public in

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[9] The following section makes heavy use of quotations from specific ideas submitted to the National Dialogue site. In some cases, ideas were edited from their original form for reasons of spelling and grammar, but are otherwise quoted verbatim from the original National Dialogue site. While most of the ideas are excerpted in part, all of them can be viewed in full in their original form at http://www.thenationaldialogue.org/healthit.

governance and soliciting their viewpoints on issues of relevance to them. It is the view of the Panel that producing solutions on health care—as well as on a host of other issues—will require precisely this sort of enhanced, intensive public engagement.

Today, Americans are faced with myriad challenges: attaining energy independence; repairing our financial markets; creating jobs; investing in our national infrastructure; tackling climate change; and reforming our educational system. Making serious progress on any of these issues will require more than just transparency. Transparency is a procedural virtue, but true progress will result when citizens are empowered to engage in the process of governance and armed with meaningful information about the options, costs and impact of their choices. Accordingly, real change will depend on government's ability to clearly put choices before the public. Having public priorities and concerns reflected in the policy decisions that emerge is a fundamental prerequisite for a durable and credible policy consensus.

The Importance of Neutral, Independent Expertise

The Panel appreciates that OMB, GSA and the Federal Chief Information Officers Council recognized the importance of having the independent judgment and subject matter expertise of the National Academy and its Fellows brought to bear in engagements like the National Dialogue. While platforms like the Dialogue are powerful tools for soliciting and organizing large amounts of public input, there remains an important role for such neutral experts in placing this feedback in broader context and synthesizing it into actionable recommendations for leaders in government and the private sector. The National Academy's Congressional Charter establishes a mandate to "assess the effectiveness, structure, administration, and implications for governance of present or proposed public programs, policies, and processes, recommending specific changes,"[11] and pleased to have the opportunity to exercise this mandate as a facilitator of and home for such initiatives.

Taking into account each of these observations, the Panel makes the following recommendation:

> **Recommendation #1: The Panel recommends that the Administration make a public commitment to further exploration of methods of public engagement, such as the National Dialogue, that give participants the opportunity to share their ideas; provide clear choices regarding public policy options; focus on building durable consensus on national issues; and are informed by the application of independent, neutral expertise to the ideas, concerns, and priorities that emanate from such engagements.**

The Panel feels strongly that efforts like the National Dialogue have potential to directly and significantly impact the likelihood that major health care reform legislation will be passed during this Administration, as well as the quality of the reform effort.

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[10]   "The Change We Need | Technology." Barackobama.com. <www.barackobama.com/issues/technology>
       December 6, 2008.
[11]   "About the Academy: Congressional Charter." National Academy of Public Administration.
       <http://www.napawash.org/about_academy/congressional_charter.html> November 28, 2008.

Recommendation #2: The Panel recommends that the Administration continue the conversation begun in this National Dialogue with enhanced efforts to engage a broad stakeholder community around issues of health IT, privacy, and ultimately, the overall delivery and quality of health care in this country.

Drawing on some of the observations made elsewhere in this paper, particularly the "Lessons Learned" section, the Panel recommends several specific opportunities for refining such initiatives in service of better fulfilling the commitment to transparency and openness that the National Dialogue signifies.

Recommendation #3: The Panel recommends that efforts to refine the National Dialogue process focus on improvements in the following areas: timing and logistics; broader and more successful outreach; implementing a multi-stage process that yields more concrete feedback; more effective mechanisms for prioritizing and ranking the content generated by participants; enhanced collection and analysis of demographic data about participants; and the addition of in-person interactions to ensure representation of the views of people who lack ready access to the Internet.

In analyzing the substantive outputs of this National Dialogue, the Panel noted the Dialogue succeeded in touching on four issues that are in a sense the building blocks of health care and health reform in this country: the quality of health care; the potential of health information technology to enhance care and produce better health outcomes; the protection of personal privacy; and the efficiency of systems that support the use of this technology. However, the Panel also observed that while each of these "building block" issues was addressed, they were discussed largely in isolation from one another, rather than in an integrated fashion.

Discovery of a "Personal Health Care/Other Use" Dichotomy in the Discussion

In assessing why this fundamental connection was not powerfully reflected in the National Dialogue, the Panel discovered an important theme that may provide a roadmap for future public engagement on the topic of health information technology and privacy. It is the Panel's observation that the discussion was defined by a pattern that may be best described as a "personal care—other use" dichotomy. In discussing various proposals and concepts dealing with the use of health information technology, Dialogue participants seemed to draw a distinction between proposals that dealt with their own personal care, and those that seemed to affect "other use" issues such as public health, research, and medical practitioner training; by and large, participants were more comfortable with and responsive to the former, and were less comfortable with the latter. In other words, participants largely envision a model of health care that has their own personal health care in the center, and sees other uses of health information as being outside of, but potentially useful to that care. This pattern may also be viewed as a concentric model:

Direct Relevance to Patient Care

Discovery of Best Practices; Relevance to Large Groups

Discovery of New Technologies; No Guaranteed Relevance to Patient Care
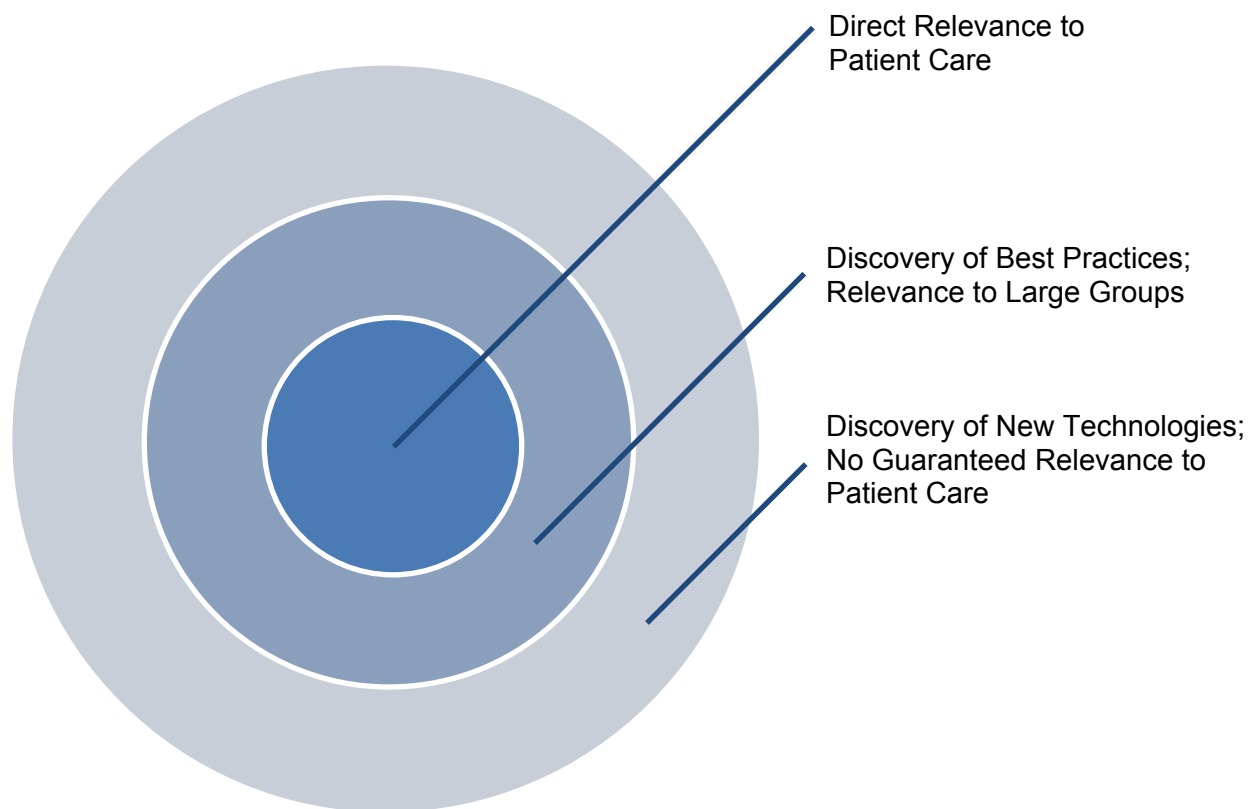
Figure 1: Concentric Model of Personal Health Care-Centric View of Various Uses for Health Data

The three tiers in this model conform to the following general pattern:

- *Tier 1*—Electronic data sharing that is directly relevant to patient care; data is shared among practitioners, all of whom have professional responsibility to the patient.
- *Tier 2*—Data sharing in order to ascertain best practices with respect to the treatment of a specific ailment or other difficulty, which suggests benefits for people with whom the patient has sympathy/empathy.[12]
- *Tier 3*—Data sharing in order to develop new technologies to the treat certain ailments, but which are not guaranteed to produce better care and may not have direct relevance to patients.

The Panel views the person as the center of the health care universe and the person-provider relationship being the primary care relationship and—contrary to this concentric model—sees the broader, research-oriented public health uses of health data as being inextricably linked to patient care. Research based on appropriately aggregating patients' health information can lead

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[12] Patients frequently participate in illness- or treatment-specific groups, and frequently say, even in malpractice suits, that they want to ensure that "what happened to them would not happen to anyone else."

to the discovery of important trends, policy innovations, and ultimately, new solutions that all redound to the benefit of personal health care and health outcomes.

Moreover, the data sharing that enables technological innovation is critical to reform of America's health care system. Senator Max Baucus (D-Mont.), who chairs the Senate Finance Committee—a key committee for passing any health care reform measure—has said that health IT "represents the beginning of health care reform."[13] Senator Edward M. Kennedy (D-Mass.), who chairs the Senate Health, Education, Labor and Pensions Committee—another committee through which any reform measure would have to pass—has likewise stated that "modernizing our health-care system through better use of information technology is the key to easing the heavy burden of health-care costs."[14] President Obama himself echoed these sentiments in his first White House press conference since taking office, linking the benefits of health IT investment directly to the strength of the overall economy:

> We know that health care is crippling businesses and making us less competitive, as well as breaking the banks of families all across America. And part of the reason is, we've got the most inefficient health care system imaginable. We're still using paper. We're still filing things in triplicate. Nurses can't read the prescriptions that doctors -- that doctors have written out. Why wouldn't we want to put that on an electronic medical record that will reduce error rates, reduce our long-term costs of health care, and create jobs right now?[15]

The Panel concurs, and sees the use of health information for supporting a person's care and health as existing in a mutually-reinforcing loop with more research-oriented and public health uses, not as separate from or antithetical to them. Ultimately, while not all technological advances are guaranteed to redound to the benefit of patient care, attempts to reform America's health care system cannot succeed without the cost savings and increased effectiveness that can only be gained from deploying new and innovative technologies. As such, the Panel believes strongly that a discussion that integrates all of these topics must form the basis for future efforts to improve the quality and effectiveness of health care in this country, and ultimately, the health of its people.

> **Recommendation #4: The Panel recommends that future efforts to engage the public on issues of health IT and privacy proceed from the objective of helping participants understand the connections between a person-centered view of health care information and the benefits of using personal heath care information for appropriate broader purposes.**

The discovery of this "personal care–other use" dynamic is extremely important, and demonstrates the potential value of pilot initiatives like the National Dialogue to reveal the

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[13] Brewin, Bob. "Obama pledges to pursue health IT, despite economic woes." Nextgov.com. <http://www.nextgov.com/nextgov/ng_20081212_8804.php> December 12, 2008.

[14] Connolly, Ceci. "Obama, Lawmakers Expanding Health Measures in Stimulus Plan." The Washington Post. December 12, 2008.

[15] Obama, Barack. "Press Conference of the President." East Room, The White House, Washington, D.C. February 9, 2009.

contours of public thought on a given issue. Such a discovery is a first, critical step to implementing policy that successfully addresses these concerns and gains enduring public support.

In addition to this overarching finding, the Dialogue elicited a number of informed and insightful comments that were both important to the community of participants engaged by this effort, as well as relevant to the broader debate on this issue. With an eye towards highlighting this feedback, the Panel undertook its analysis under the premise that it could be usefully placed in the context of broader themes.

The basis for this analysis was the rating mechanism that allowed participants to bring the "best" ideas to the forefront of the discussion. The Panel adopted the following initial criteria for highly rated ideas: any idea that earned a rating of 4 or 5 from Dialogue participants, and attracted more than five comments and two votes. However, to accommodate limitations of both time and volume, these criteria were used only as a point of departure for analysis, with the Panel enlarging or reducing its focus on ideas as it saw appropriate. Ultimately, the Panel found within the Dialogue a number of useful and interesting submissions that do much to advance the conversation on health IT and privacy.

This analysis yielded three overarching themes of discussion:

- ***Health and Privacy Trade-Offs***—discussions concerning the tension that is said to exist between enhanced use of health information technology and reliable safeguards of personal privacy.
- ***Health Information Technology***—ideas and suggestions about how best to harness the power of existing and emerging technologies to more effectively manage and share health information.
- ***Health IT Best Practices***—proposed best practices for those that engage in the collection and use of health information.

Health and Privacy Trade-Offs

The issue of "trade-offs" between enhanced use of health information and the safeguarding of personal privacy is one that has defined the debate on this issue. It is the view of the Panel, however, that in much the same way that personal care and "other uses" of health information are inextricably linked, the issues of technology and privacy are in fact mutually reinforcing. More effective systems for managing information are a prerequisite for more effective—rather than simply more restrictive—privacy practices, and in turn, more responsive privacy practices are a key to developing information management systems that can obtain assent and participation from people with a wide range of views on that issue. Accordingly, the Panel believes that parties within and outside of government must work towards crafting affirmative policies that incorporate both issues and do not see them as being necessarily opposed.

> **Recommendation #5: The Panel recommends that future efforts to engage the public on the issue of health information technology and privacy should be directed towards finding a synthesis of concerns about information use**

and privacy, rather than let the debate be focused on and governed by the extreme positions on these issues.

The discussion on this topic within the Dialogue mirrored this view. While participants did not use the platform to generate a clear synthesis of IT and privacy, many grappled directly with the need for such a synthesis and offered early indications of how one might begin to take shape.

Another idea that was important in getting beyond the extremes that often define this debate was phrased as a simple question: **How Do Privacy Concerns Affect Adoption of HIT?** The submitter made an admirable attempt to replace "conventional wisdom" with empirical reality:

> How much do privacy concerns actually affect adoption rates of HIT (per consumers and per professionals)? Do we have actual causation, or just theories relating to correlation?

> Amidst discussion of HIT adoption and the need to protect personal health information is the oft-discussed theme that privacy concerns negatively affect adoption. What kind of evidence exists proving or disproving this theory? How should we approach the issue of the relation between privacy concerns and adoption?

The comments on this idea elicited a host of references to clinical studies, informal polls, and anecdotes. Debates both within and outside this Dialogue platform indicate that the question of whether and why health IT adoption might be affected by privacy concerns is an important one.

A similar concern is reflected in the user comment, **Health IT Policy and Commentary Should Be Evidence-Based**:

> The debate about whether health IT improves quality or lowers costs is governed by a standard that is different from the one that governs the question of whether particular medical services and devices improve quality or lower costs. The standard that has governed the latter debate for the last two decades -- evidence-based medicine -- is based on the belief that the decision about which medical services to recommend and pay for should be based on scientific evidence (to the extent it is available). The debate about health IT is not governed by an equivalent [sic] standard, one we might call "evidence-based health policy."

> Thus, to take the most prominent example of the problem, even though the literature on electronic medical records is mixed on the question of whether EMRs improve quality, and even though the literature does not support the claim that EMRs reduce costs, health policy experts and politicians claim EMRs save money and cut costs and that making EMRs interoperable will make EMRs even more potent as quality-improvers and cost-cutters. This cavalier attitude toward evidence would be derided if it were expressed by a doctor (say, a spine surgeon) or a drug company. But when it is expressed by the Institute of Medicine, Newt Gingrich, Hillary Clinton, George W. Bush, Bill Gates, or scholars at the RAND Corporation, this attitude is considered quite acceptable, even the height of wisdom.

The author of this submission takes a much more skeptical tone towards the promise of medical technology than the Panel; the Panel feels that thoughtful deployment of such technology is critical to achieving the quality improvements and cost reductions that are central to any serious health care reform efforts. However, the submitter's overarching point is well taken, as it reflects what the Panel sees as a broader skepticism about the real benefits of health IT among the general public. Addressing this skepticism must be an integral part of President Obama's commitment to engage the public directly on the issue of health care reform.

This is particularly troublesome in today's economic climate. Today, it is widely believed that health care reform is integral to achieving a broad economic recovery. Particularly because of the expected stimulative impact of any potential health care reform, it is critical that the new administration make its case for reform based on empirical data, and ideally, make this data available directly to the public so that engaged citizens can perform their own analysis. Doing this would both increase the chances of successful reform, and enhance public investment in whatever reform ultimately emerges.

> **Recommendation #6: The Panel recommends that future efforts to engage the public on the issue of health information technology and privacy should place an emphasis on quantifying and clarifying the potential cost reduction and quality enhancement benefits of expanded use of health IT, and the effect that privacy concerns play in health IT adoption. Efforts should also include a component that makes the analysis and the raw data underlying the empirical case for various aspects of health care reform directly available to the public.**

Engaging the public effectively around health care reform will also require accurately framing the various trade-offs that consumers' should expect to face as a result of reform. Getting this aspect of the debate right is particularly important because any durable consensus on the issue will ultimately require synthesizing trade-offs between extreme positions into a single policy. In an attempt to move towards such a position, one Dialogue participant submitted the idea, **Privacy and Access in Perfect Balance**. The title of this idea alone is notable, as it provides an unusually apt summary of the kinds of choices citizens face. Although the debate is usually framed this way, privacy does not in any way stand opposed to greater use of technology per se. Indeed, technology can be used to enhance privacy, and as indicated above, the potential of advances in technology to better accommodate changing privacy concerns casts this dichotomy in a false light. Making privacy and access the subjects of public deliberation is a more realistic and reasonable choice precisely because they can contribute to each other reciprocally rather than being in opposition.

This contribution goes on to argue:

> What is needed is an easy-to-use, web-based solution that allows patients and health care professionals to control the privacy and accessibility of confidential health information. At its core, this technology needs to empower and protect the individual consumer's right to decide specifically who has access to their health information, under what

circumstances it may be used and for what purpose, as well as who cannot access or use it.

Rather than being connected to a single record holder such as a PHR, EHR or record repository (whether paper or digital), the system should aggregate privacy directives and longitudinal consent across disparate clinicians' offices and other record holder entities, and should be organized around the individual consumer or patient so that he or she does the work once and it applies to wherever his or her record is held.

The core suggestion here is of a vision of health information being managed directly by the patient, and being done so by aggregating data from a variety of discrete sources. One might think of this as a core component of a "virtual health system," one in which information generally resides where it is generated but it is available in real time and in a semantically standardized way. This innovative suggestion is very much in line with the growing power of technology to share or aggregate information in general, and the increasing rise of platforms that do so with respect specifically to health information. The importance of this development from a technology perspective is discussed in more detail in the section "Health Information Technology" below. More relevant here is the proposal of a new paradigm for managing information that emphasizes the importance of information itself over the location of that information relative to a particular record. This could allow enhanced agility in meeting the information needs of various care providers in a way that is more responsive to the needs of patients. Ideas like this exemplify how a true "synthesis" of access and privacy can ultimately be reached through enhanced technology, and smarter use of technology.

These contributions all help shape the broad contours of debate on this issue. Even when a clear choice has emerged at this broad level, however, an exercise that is truly useful to policymakers will require participants to choose among more explicit policy options. One submission to the Dialogue, **Nine Core Principles for Health Information Technology**, attempted to provide a framework for exactly that, noting insightfully that "fair information practices must guide the national discussion to expand the benefits of health information technology and protect privacy" and that "to establish the trust necessary to realize the full potential of health information technology, clear privacy attributes must be translated into appropriate business rules, policies, and practices."

The nine principles proposed are:

1. **Openness and Transparency** (Is it easy to understand what policies are in place? How they were determined? How to make inquiries or comment? Is it clear who has access to what information for what purpose?)
2. **Purpose Specification and Minimization** (What is the purpose of gathering these data? Are the purposes narrowly and clearly defined?)
3. **Collection Limitation** (Are only those data needed for the specified purposes being collected, and are subjects fully informed of what is being collected?)
4. **Use Limitation** (Will data only be used for the purposes stated and agreed to by the subjects?)

5. **Individual Participation and Control** (Can an individual find out what data has been collected and exercise control over whether and with whom it is shared?)
6. **Data Integrity and Quality** (How are data kept current and accurate?)
7. **Security Safeguards and Controls** (How are the data secured against breaches, loss or unauthorized access?)
8. **Accountability and Oversight** (Who monitors compliance with these policies and how is the public informed about violations?)
9. **Remedies** (How will complaints be handled, and will consumers be able to respond to or compensated for mistakes in decisions that are based upon the data?)

While this list is neither perfect nor exhaustive, it is a good point of departure for future deliberations, and in particular would make a good basis for efforts to have citizens choose among defined policy options. Delineating clear public preferences along each of these issue dimensions would significantly advance policymakers' ability to produce policy that is in alignment with these preferences.

A final, critical step in forging a consensus position is enhanced granularity—in particular, identifying discrete types of information that might require different levels and types of protection. Two submissions to the Dialogue dealt with this topic directly.

The first, entitled **Categorize Information for Different Security Treatment**, aptly sets out the broad contours of this issue:

> When it comes to security and privacy issues, one size does not fit all in the health data world. The broad Federal agency security policies, like the Veterans Affairs, need to be adapted for nationwide health information sharing.

> Categorize health data into different tranches that require varying levels of security and privacy provide us the opportunity to treat health data in an optimal way. We also do not need to reinvent the wheel in terms of looking for framework to categorize. We can look at how the Federal Intelligent agencies, Department of Justice, Federal Health Architecture Agencies, music and financial industries are sharing data in their value chains and ecosystems.

> Even though in general health data is more complex and consumers are understandably more guarded in the current US social health environment (where payers, providers and consumer interests are not aligned), we can learn from the banking system, music industry and the DoJ how they have categorized the data for optimal sharing, what entities are "trusted entities" and what data sharing is "routine" and "non-routine."

The submitter specifies specific models that can be emulated in categorizing health information:

> We should leverage the information sharing work that our government has done by OMB's Line of Business initiative, DoJ's National Information Exchange Model (NIEM)

and HHS' work on Nationwide Health Information Network (NHIN), and NHIE's work with providers (i.e. local Veterans' hospitals and community hospitals) on policies to share patient data to explore how industry and agencies are creating data sharing agreements as a start of a data access and sharing framework for consumers sharing health data with trusted entities.

One response to this idea attempted to actually define categories for health information based on their use:

> Categories of data: 1) for use by providers in patient treatment, 2) for personal use to manage own health, 3) to protect populations in case of epidemics, etc., 4) for health insurance purposes, 5) for evidence-based research. In 1 & 2, there are physical and mental health data. In 3, people with AIDS, etc. would be identified. 4 could be discriminatory. Only 5 would the data may be [sic] de-identified to protect privacy.

One specific type of information—that dealing with mental health—was singled out for special attention during the Dialogue. The idea **Privacy of Mental Health Information** provides an informative overview of the issue landscape for mental health information, and commenters note that mental health is an area of medicine in which, more than others, treatment for patients may be rendered ineffectual if they do not feel secure in the confidentiality of their information.

Overall, although they did not express it in precisely these terms, it is clear that participants in the National Dialogue placed a high premium on identifying, quantifying, and reconciling the various trade-offs surrounding health IT and privacy, towards the goal of synthesizing a durable consensus view point.

Health Information Technology

While the debate over how best to use health IT often relies on a static conception of "technology," new technologies are constantly being developed that advance our conception of what is possible. Discussion in the Dialogue recognized this fact, and indeed was focused primarily on transparency, open-source software, and technical schemes for implementing patient ownership of information. While these themes are not reflective of the totality of capabilities that are available thanks to technological advances, they do represent a slice of that debate and, importantly, the one that was given prominence by a many participants in the Dialogue.

The thread running through topics of transparency and open-source software is the desire for accountability. Participants in the Dialogue generally wanted to understand and be more involved in the systems that are used to manage their data, and wanted them to be more agile and able to evolve to changing needs and best practices. Open source platforms in particular received a relatively high level of support. While this finding in particular may be an artifact of the fact that the National Dialogue's participant base was likely more tech-savvy than the population as a whole, this desire nonetheless mirrors an emerging field of technology development within the broader IT community.

The most prominent expression of this sentiment in the Dialogue was a submission entitled **Transparency in Health Care**. The submitter argued that "transparency has the potential to structurally transform our health care system," adding:

> The democratization of government data has revealed an enormous appetite for civic participation. We should leverage the power of democratizing data to start a technology revolution in health care. Without violating privacy, today, we have the ability to publish enormous amounts of data that would reveal the inner workings of our health care system, so we could finally begin to transform it.

The conversation sparked by this comment included a host of important points:

- Transparency enhances the clarity of choices facing users of the health care system.
- Transparency creates clear lines of accountability for the performance of the system.
- Government has a potentially important role in creating and maintaining an incentive structure that promotes transparency among private-sector actors.
- Privacy concerns may ultimately be alleviated by enhanced transparency, since it is the seeming "black box" that defines current systems that generates many privacy concerns.

This submission to the Dialogue was particularly notable because of its author. Vivek Kundra, the Chief Technology Officer for the District of Columbia, is widely recognized as a leader in enhancing public engagement and service delivery through the transparent use and aggregation of data. Kundra himself cites this work in this submission:

> The District of Columbia maintains vast stores of data on every aspect of government operations, from government contracts to crime statistics to economic development. We have organized this data into convenient catalogs and live data feeds and made them available to the general public at http://data.octo.dc.gov.

> When we first opened the doors to government data, people were quick to respond. Individuals and organizations are not only viewing our government data, but are actually improving upon our work by analyzing and repurposing the information in useful ways. One innovative DC resident took it upon herself to gather publicly-available government data on service requests, crimes, and building and public space permits to create a website that informs southeastern DC residents about local real estate development and the quality of government services. The Knight Foundation, a non-governmental organization, transformed District data into an online community news forum at EveryBlock.com. Here, visitors can plug in their zip code and find and exchange information about everything of interest in their neighborhoods—local businesses and reviews, crimes, road construction, community meetings, and more.

The management of health information—data which is ostensibly meant to remain confidential or at least non-personally identifiable—would pose obvious challenges for this model. Nonetheless, Kundra's work compellingly demonstrates the great potential of transparent data management practices for gaining public trust, enhancing civic engagement, and increasing understanding of otherwise impenetrably complex systems.

Taking this line of thinking a step further, there was also support for a submission that exhorted participants to **Insist on Open Source**. The submitter's argument pointed out that traditional proprietary systems can block innovation and fail to respond to advances in technology or changing consumer needs:

> Those deciding on health IT solutions should insist on Free and Open Source (FOSS) software.

> When people use proprietary Health Information systems, there is always one party, the developers of the proprietary system that has a dramatically skewed proportion of the control of the health information.

> People will suggest many wonderful ideas on this board: PHR's, transparency, consumerism, Health 2.0, interoperability etc etc. But if those good ideas are implemented in proprietary systems, then the true "owners" of the health information are the vendors. They are the only ones who can change what the software needs to do.

> This is important because we have no idea what a Health IT applications should be doing in two years.

The submitter also points to a precedent for developing such a system within government: the U.S. Department of Veterans' Affairs Veterans Health Information Systems and Technology Architecture, known as VistA:

> As a result of a rigorous system of performance measurement and improvement supported by VA's electronic health record system, VistA, veterans treated by VA now receive "the best care anywhere." A recent RAND study found that VA outperforms all other sectors of American health care across the spectrum of 294 measures of quality and disease prevention and treatment. For six straight years, VA has led private-sector health care in the independent American Customer Satisfaction Index.

> While the costs of health care in the United States continue to soar, VistA is reducing costs and errors and increasing safety and efficiency. The price of maintaining the system is $87 per patient per year, less than the cost of one unnecessarily repeated lab test.

> VistA enables VA clinicians to view electronic health records, including images, throughout VA's 1,400 site system. The foundation of a personal health records system helps veterans successfully manage their own health.

> The involvement of front-line providers, use of performance measures and universal use of electronic health records have enabled VA to set the national benchmark in quality of care. VistA's computerized system enables key decisions by checking links to automated drug distribution, leading to a significant reduction in the error rate. As many as one in seven hospitalizations occur unnecessarily because records are not immediately available

and as many as one in five lab tests is needlessly repeated. It also provides telehealth outreach to rural and isolated veterans. 16

VistA was awarded the Innovations in American Government Award by Harvard University's Kennedy School of Government in 2006. The Dialogue submission on open-source cited above used VistA's development to sketch out basic principles for open-source development:

> Arguably…the best EHR in the world is VA VistA. It is the best because it was developed with the following way:
> * Openly, everyone could see the code
> * Collaboratively, different people did different parts focusing on solving local needs.
> * Distributed, there was no central body who created the "specs" for VistA
>
> That is essentially the open source development model.
>
> Freedom is not incidental to the quality of VistA. It is the foundation of VA VistA. Without the local control and the centralized coordination that are the hallmarks of the [Free and Open-Source Software] development model, we will never realize the potential for software to improve health care

In comments to this submission, it is suggested that VistA's success is due at least in part to the Department of Veterans' Affairs exclusive and relatively bounded universe of patients. However, the Dialogue also discussed several efforts to create FOSS solutions outside of government:[17]

* TriSano, "an open source, citizen-focused surveillance and outbreak management system for infectious disease, environmental hazards, and bioterrorism attacks."[18]
* Dossia, "an independent secure, non-profit infrastructure for gathering and securely storing information for lifelong health records."[19]

Although transparent information management systems have great potential, they are only half of the equation. The other critical component is patient and consumer education. Systems that are more responsive to consumer preferences require that consumers be able to articulate those preferences, and accordingly, that they be more aware of the choices and trade-offs to be made when managing their health information.

This question was raised in the Dialogue in the simple form, **What Role Does Patient and Consumer Education Play?** The submitter provides a deft summary of the importance of education:

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[16] "Fact Sheet." VA VistA Innovations Award Home.
<http://www.innovations.va.gov/innovations/docs/InnovationFactSheet.pdf> July 13, 2006.
[17] The recognition of these systems within this report is not meant to be, and should not be construed as, an endorsement or even a comprehensive assessment of the systems' features or future potential.
[18] "Trisano." Trisano.org. <http://www.trisano.org/> December 6, 2008.
[19] "Dossia – About Us." Dossia.og. <http://www.dossia.org/about-us> December 6, 2008.

Transparency and consumer education are related, but different things. Transparency is required for good education, but simply doing a 'brain dump' doesn't generally help patients and consumers make good choices. How should consumers and patients - from both population and individual perspectives - be made more aware of the information that is available and how to use it?

In order to transform our health care system, we have to engage consumers and patients more fully in their health care. This requires culture change and gaining the trust of consumers. At the same time, we have to take advantage of innovative ideas, some of which may make consumers uncomfortable, especially ideas related to sharing of data electronically, payment reform and aligning of incentives. In order to achieve both goals of transforming the health care system and gaining consumer trust and engagement, we have to figure out how to communicate with AND SEEK FEEDBACK FROM consumers about the issues. Also, we absolutely must avoid tokenism, which is sometimes seen in efforts to engage consumers. This is particularly important in regard to privacy discussions, b/c just as it is important for individuals to understand the implications of sharing their data, it is also vital to understand the potential consequences of not sharing it.

There is a critical relationship between increasingly transparent health information management systems and consumers' ability to use and interact with these systems in a sensible and productive manner.

Health IT Best Practices

While it is important to maintain a focus on systems, the most fertile area for progress in the debate over health IT and privacy is on the question of *how* to use data to fuel enhanced health care. Indeed, we have recently begun to see innovative uses of data redound to the field of public health. In November 2008, Google.org—the charitable foundation arm of search engine giant Google—launched a project aimed at "us[ing] aggregated Google search data to estimate flu activity in your state up to two weeks faster than traditional flu surveillance systems."[20] Google accomplished this by noticing that queries for certain search terms, such as "flu shots," tended to spike in areas where instances of influenza were on the rise. The results of the initiative, called Google Flu Trends, were intriguing:

During the 2007-2008 flu season, an early version of Google Flu Trends was used to share results each week with the Epidemiology and Prevention Branch of the Influenza Division at CDC. Across each of the nine surveillance regions of the United States, **we were able to accurately estimate current flu levels one to two weeks faster than published CDC reports.** [Emphasis added.][21]

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[20]   "How does this work?" Google.org. <http://www.google.org/about/flutrends/how.html> December 7, 2008.
[21]   Ibid.

The success of Google Flu Trends relied not in any new technology, but in using existing data in powerful, innovative ways. As in any use of private data (e.g. Internet searches), there is a need to protect privacy in the world of the Internet.

The desire to create new and innovative ways to bring data to bear in service of improved health care was also reflected in the Dialogue.

One such idea, titled **Teach Health Professionals to Work as Teams & Use Health IT**, asserts:

> We can revolutionize health care teaching, research and delivery: Create knowledge-rich teams who use health IT to advance human health in the context of larger systems such as animal disease surveillance and public health. Professionals have to learn differently in order to practice differently; researchers have to connect their work to real-world problems and applications; isolated systems need to connect.

> Today, health care is fractured.

> We're treated by isolated professionals who were taught and practice in silos. Experts on human health don't work with experts on plant, animal or ecological health. Seldom do any cross paths with experts in policy. And the information that could help them all is cumbersome to access, lying hidden in patient data and public health records.

> Tomorrow's health care should be a system.

> Interdisciplinary research unraveled the code for DNA. Imagine a future where—thanks to a robust health IT system and people who understand and use the knowledge it holds—the learning from such boundary-crossing research is translated real-time into instruction, clinical services, and other practices and policies.

This vivid portrait reflects a critical truth: The best medical care comes not from new technology alone, but from knowledgeable, experienced practitioners who are enabled by technology and understand how to apply technology to a variety of circumstances.

Another popular submission to the Dialogue, **Create Individual Consumer Networks**, proposed using technology to empower consumers:

> Use the technology of e-mail to create indivual [sic] consumer provider networks by forming groups of providers with unique names in a directory which includes all networks. One e-mail will send information to all network members to assure coordination of care. Individual messages could be sent to one, some, or all providers according to the situation or consumer wishes. Some jobs might be created to manage the information flow

In comments to this idea, participants suggested that other technologies might be more effective in supporting health-focused communities. Indeed, platforms like wikis, social networks, and collaborative voting sites already power a number of popular online communities. This concept,

with appropriate privacy protections, supports very well the Panel's "person-centered" views on improving health and health care.

A final aspect of the best practices debate regards one specific practice: Electronic prescribing of prescription drugs, or "E-Prescribing." The Centers for Medicare and Medicaid Services describe the practice as "a prescriber's ability to electronically send an accurate, error-free and understandable prescription directly to a pharmacy from the point-of-care."[22]

The topic elicited several submissions in the National Dialogue. One, titled simply **Electronic Prescriptions**, posed two simple questions:

> What access should be allowed for E-Prescribing?

> Should physicians be able to see medications ordered by other physicians?

Responding to these questions, one commenter related the question to the personal experience of health care practitioners:

> Absolutely!

> There are few clinical practitioners in the behavioral arena who don't have a real life story that goes something like this...

> I remember jonny jones and the time he showed up at xxxx clinic. He was presenting xxxx symptoms... If only I'd been able to see that he'd picked up a prescription for yyy I would have know that what he was having was a drug interaction and not another psychotic episode. It would have prevented zzzzz from happening....

> This general story (with the specific blanks filled in) is an all to[o] common one at most emergency rooms and with mobile crisis staff responding to public safety calls. If for no other reason this data needs to be available.

> Perhaps situational protocols could be devised to pre-authorize accesses.

This raises one issue when information is not available despite the patient or consumer's preferences. It raises another difficult issue when that person chooses not to share certain information (e.g. prescription drugs) that may affect diagnosis, treatment or outcome.

In a related submission, one Dialogue participant noted that the current administration has taken steps to encourage this practice, and that Congress is looking for opportunities to do more:

> Congress has signaled its desire to see more widespread use of e-prescribing by clinicians by offering a 2% Medicare payment bonus "carrot" beginning in 2009 for using e-

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[22] "E-Prescribing: Overview." Centers for Medicare & Medicaid Services. <http://www.cms.hhs.gov/eprescribing/> October 30, 2008.

prescribing (the bonus is phased down and out by 2013). Congress also is balancing the "carrot" with a "stick," penalizing those who do not e-prescribe under Medicare beginning in 2012 (with a payment reduction of 1% rising to a maximum of 2% in 2014 and years thereafter).

Considering that only about 6% of office-based clinicians were using e-prescribing at the end of 2007, do you believe the above level of incentives/disincentives will be effective in significantly increasing e-prescribing adoption? Is this the best strategy to achieve the desired outcome? What other approaches would you propose?

The submitter is referring to the following development:

[The Centers for Medicare and Medicaid Services] on Friday confirmed details of an electronic prescribing incentive program for physicians, scheduled to begin on Jan. 1, 2009, which would increase Medicare payments for doctors who use the technology, the Dallas Morning News reports. Under the new program, which was included in the new Medicare law in July, physicians who use e-prescribing technology to deliver medication prescriptions to pharmacies will be eligible for a 2% increase in their Medicare payments (Roberson, Dallas Morning News, 11/1).[23]

There is little doubt that E-Prescribing is a critical aspect of any anticipated health care reform—and like any of the reforms mentioned in this report, would require major changes in both technology and procedure.

All of these ideas demonstrate a powerful theme coming from Dialogue participants: Advances in technology must be met by medical professionals and consumers with correspondent advances in the way we organize ourselves and our health care providers to take advantage of that technology. As more transparent and responsive platforms for sharing data begin to emerge, we will be required to formulate new best practices for ensuring that the benefits of these advances redound to the quality of overall health care received by patients and consumers.

Recognizing the importance of these issues, and building from the National Dialogue as well as further consultation with experts, the Panel has created a set of principles that it believes should guide health information use and privacy. In doing so, the Panel drew upon the National Dialogue which, though a pilot, provided much useful information both directly and indirectly about the state and contours of debate on these issues. The National Dialogue and the work surrounding it suggest that there may be an opportunity for common ground and for achieving consensus. The Panel also drew upon the body of work preceding the National Dialogue, including those documents used as background for the Dialogue. To gain further insights on a potential consensus set of principles, the Panel consulted with national experts on this issue.

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[23] "CMS Announces Several New Medicare Regulations, Including Incentive Program for Physicians Who Adopt E-Prescribing Technology." The Henry J. Kaiser Family Foundation. <http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=55333> November 3, 2008.

By drawing upon on all these sources, the Panel believes that it found potential and important common ground for a consensus set of principles. The Panel believes that these principles may be useful in moving us all from an unresolved debate to a national consensus that will help expand the use of information technology and protect personal privacy as means to improve health and health care across America.

CONSENSUS ON HEALTH IT AND PRIVACY

After careful consideration, the National Academy of Public Administration Panel of Fellows guiding the National Dialogue on Health Information Technology and Privacy has concluded, as have many others, that there is a very high value to protecting the privacy of a person's health information but that there is also a very high benefit to careful and appropriate sharing of health information to improve the health of that person, their community, and the nation. This position is based on insights from the National Dialogue and other key sources, including Connecting for Health, the Office of the National Coordinator for Health Information Technology (ONC) and the Centers for Medicare and Medicaid Services. People strongly hold differing views on this issue, especially at the two ends of the spectrum from maximizing personal privacy protection to maximizing personal health information sharing.

Based on the insights gained, the Panel has also concluded that the time has come to resolve this issue in a way that carefully and appropriately protects personal privacy and carefully and appropriately shares individual health information. At this point, progress requires agreement on a coherent set of principles rather than individual responses to opportunistic situations as they arise. A solution based on the principles below or similar principles can and should strike the appropriate balance of protecting personal privacy and improving health. We encourage all parties to quickly move to the best solution consistent with this position.[24]

In our view, the best solution should follow these principles:

Individual Person
- The person (e.g. consumer, patient, beneficiary, member) is at the center of the health system with the primary relationship being a partnership between the person and his/her health care provider. Outside of that partnership, many others have a unique role with the payer (other than self-pay) and need access to information. The other participants can also serve very important roles (e.g., research, threat surveillance (naturally occurring diseases and intentional exposure to diseases), public health) that directly or indirectly affect a person's health. Employers, beyond their role as payers, can also directly or indirectly affect a person's health care.
- A person should know what individual health information is being collected, for what purpose, and for what use.
- Except where required by law, the individual should have ultimate control over who their personal health information is shared with and for what purpose.

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[24] This recommendation is solely the responsibility of this Panel, and does not necessarily represent the views of the National Academy of Public Administration or any of the federal entities responsible for initiating the National Dialogue project.

- The person should have access to all of their personal health information, be allowed to make corrections and have an audit trail of its use. We recognize there are a very limited set of circumstances when a health care provider may hold back information for a limited time to protect the person or the public from harm.

Environment
- Privacy policy-making and policy implementation should be conducted in an environment that is open and transparent.
- The person should be empowered to have their personal heath information provided to a personal health record site or system that enables them to control access.
- The person's consent is not required when it comes to making required reports to public health authorities for reportable diseases and to the police, such as reporting gunshot wounds.
- The collector, holder, user and transmitter of a person's health information should be and will be held accountable and enforce the privacy requirements.
- Remedies should be available for making complaints and for harm to the person.
- For the purpose of non-direct care uses, a person's consent for use of <u>personally identifiable information</u> is necessary and must be specific and limited to the particular use with appropriate safeguards. These non-direct care uses include research (with adherence to standards of practice regarding Institutional Review Board oversight), quality monitoring and improvement (e.g. by Quality Improvement Organizations), threat surveillance (naturally occurring diseases and intentional exposure to diseases), public health, marketing/advertising, and a person's employer or insurer analysis of payment related data.
- For the purpose of non-direct care uses, a person's consent for use of truly <u>de-identified information</u> may not be necessary, but only if the person's information is truly de-identified. The person should be advised of these potential uses of de-identified personal information and may decide not to consent to any of these non-direct care uses. These non-direct care uses include research, quality monitoring and improvement (e.g. by Quality Improvement Organizations), threat surveillance (naturally occurring diseases and intentional exposure to diseases), public health, marketing/advertising, and a person's employer or insurer analysis of payment related data.

Synthesis
- A solution based on these or similar principles can and should strike the appropriate synthesis of protecting personal privacy and improving health.
- For the purpose of providing direct care by a health care provider, a person's consent is necessary but can encompass all current and future care by that provider and by other health care providers. It can also include the sharing of information in the case of an emergency, as needed.
  - A person should be given the option of not sharing particularly sensitive information (e.g. mental health, alcohol and drug abuse treatment) but should also be advised that this may limit a health care provider's ability to provide the best and most appropriate care.
  - A person should have the option of restricting sharing further but should also be advised that this may limit a health care provider's ability to provide the best and

most appropriate care. Liability provisions should protect providers who deliver care and make decisions without access to information that a person has chosen not to share.

- A person should have the option of sharing information with person(s) (e.g. family) whom they choose, especially those assisting them with their care and bill payment.

- In those very limited emergency cases when consent cannot adequately be given and has not been given previously, a "break-the-glass" option that does not contradict the person's expressed consent limitations may be necessary to serve the best interests of the person/patient.

- For the payment-related purposes, a minimally reportable subset of the person's personally identifiable information may be shared with their payer (health insurance companies, HMOs, most employer group health plans, and certain government programs that pay for health care, such as Medicare and Medicaid.

- Information that is personally identifiable or could be made personally identifiable should be subject to very strong security (protection against breaches, loss or unauthorized access and use) using the most effective methods currently available for securely storing, using and sharing information within a health care provider, across health providers for the purpose of direct care and for other approved uses, e.g. payment.

METHODOLOGY AND RESULTS

TECHNOLOGY PLATFORM AND USER EXPERIENCE

The technology platform that powered the National Dialogue was a core component of the initiative, affecting both front-end user participation and back-end analysis and reporting. The custom-built platform was designed to solicit users' best ideas, encourage dialogue and debate, provide tools for socializing the discussion, and use rating and tagging functionalities to highlight points of agreement and important themes. Similar platforms have been used by organizations ranging from Starbucks Corporation and Dell Computers, to the Transportation Security Administration and U.S. Patent and Trademark Office, to solicit large volumes of feedback across a wide spectrum of opinion, and synthesize that feedback into discrete, actionable guidance for policymakers.

The solution engineered for the National Dialogue was based on a number of core principles:

Lower Barriers to Entry

Because the success of the National Dialogue depended on both the volume and diversity of opinion, a choice was made to lower the number and complexity of steps that potential participants would have to go through before joining the conversation. The signup process for the National Dialogue consisted of a short one-page form soliciting simple personal and demographic information.

Ensure a Value Exchange

Another key aspect of ensuring participation was providing potential participants with a clear and plausible value exchange—what they could expect to gain for their time spent submitting or rating ideas. In this case, the chief value exchange was twofold: the chance to engage with perspectives that one might not otherwise encounter; and the chance to influence policymakers by participating. The latter was especially powerful and was presented to participants with the following language:

> The national discussion produced concrete, actionable suggestions for government leaders. A Panel of Fellows from the National Academy of Public Administration is distilling the results of this dialogue into a report that captures "citizen-centric" recommendations. The report will be presented to the transition team for the new Administration, as well as OMB, the United States General Services Administration, the Federal CIO Council, and other relevant Federal agencies.

Time Limit the Discussion

Providing a concrete beginning and end to the discussion period incentivizes early and repeated participation, as users naturally use the latter half of a defined discussion period to refine and rate ideas, rather than submitting new ideas. A time limited discussion also provides a focused and

urgent opportunity for participation, which urges potential participants to visit the site immediately, rather than making time for it "later."

Solicit the "Best Version" of Feedback

Although one stated purpose of the National Dialogue was to solicit a large quantity of ideas from users, the platform also included structural elements aimed at promoting the quality of these submissions. Before submitting an idea, users were asked to "bucket" it into one of four categories—Idea, Concern, Story, and Principle—and to fill out a separate text field to answer the question, "Why Is This Important?" Both of these features encouraged users to give careful thought to the context and relevance of their submissions before posting the comment. This resulted in better crafted and accessible submissions. In turn, this ensured the scalability of the Dialogue by increasing the likelihood that a participant could add their vote or comment to an existing submission, rather than creating a new submission that differed only slightly from a pre-existing one.

Track, Guide, and Focus the Discussion

While users spent most of their time on the site engaged with individual ideas, the National Dialogue project team sought to avoid them. To address this, the team recruited a small group of "Discussion Catalysts"—respected subject matter experts who were charged with making sure the dialogue was constructive, exploratory and built on previous research or advances made in relevant areas. However, they were advised not to "steer" the dialogue in any particular direction. They performed their role primarily by actively participating in discussion threads throughout the site, with their feedback highlighted visually for added emphasis.
A listing of the Discussion Catalysts is contained in Appendix B.

Provide Clear Ground Rules

Honest and open discussion can only take place in an environment where all parties understand the ground rules of debate. A brief and intelligible list of "Moderation Rules" was posted on the National Dialogue website, listing what behaviors would result in the deletion of a user's input:

> The National Dialogue pilot allows you the opportunity to fill out custom text fields, which are publicly visible. The site therefore operates a moderation policy to ensure that your comments are appropriate and not harmful to others. Comments which include any of the following may be deleted at the discretion of moderators:
> - Personal attacks made on the basis of race, religion, gender, nationality or sexuality or other personal characteristic
> - Excessive profanity
> - Threats or incitements to violence
> - Duplicate posts
> - Advertising products or services
> - Posting irrelevant information
> - Revealing your own or others' sensitive/personal information (e.g., Social Security numbers)

- Information posted in violation of law, including libel, condoning or encouraging illegal activity, revealing classified information, or comments which might affect the outcome of ongoing legal proceedings[25]

These rules helped ensure that the National Dialogue was a safe space for the free discussion of ideas and opinions. Indeed, during the weeklong Dialogue, only one idea was removed by moderators because it was a duplicative submission that had already been posted by the same user.

In addition, upon registering for the site, participants received a welcome e-mail with five tips to support a healthy online dialogue:

1. **Schedule Time Now.** The dialogue is open from October 27th to November 3rd at 8:00 p.m. EST. We recommend you take a moment now to schedule a few 30-45 minute time slots on your calendar so you can add your opinion as the dialogue evolves.
2. **Keep Posts on Topic.** There are many important conversations about health care in America, but this dialogue is specifically focused on the convergence of information technology, health care and privacy.
3. **Be Respectful and Tolerant.** Voice your opinions in a tasteful manner. It's okay to disagree. It's NOT okay to attack other participants personally. Be polite even when you are angry. If you are too angry to be polite, do not post, or send a private message instead.
4. **Comment and Vote.** Deepen the dialogue by using the comment feature to respond to ideas that interest you. Vote on ideas you like (or do not like) to help organize information on the site. Be sure to use the Discussion Topic tagging feature too. See http://www.thenationaldialogue.org/healthit/info/how_to_use for more info.
5. **Don't Advertise.** Please refrain from advertising for a product, service or organization.

Ultimately, the platform that emerged from these rules provided users with four overall categories of activity:

- **Learn**—users familiarize themselves with the issue, either by reading background material in the "Learn" section or clicking on any of a number of randomized "discussion questions."
- **Explore**—users explore the ideas and feedback that have already been submitted in order to gain context for the discussion and identify potential areas for participation.
- **Participate**—users contribute their own feedback, whether by submitting new ideas or by discussing, tagging, or rating ideas that have already been submitted.
- **Socialize**—users take advantage of social networks and social media sites to bring others into the conversation, enhancing the volume and diversity of feedback.

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[25] Moderation Policy. The National Dialogue homepage. <http://thenationaldialogue.org/info/moderation>

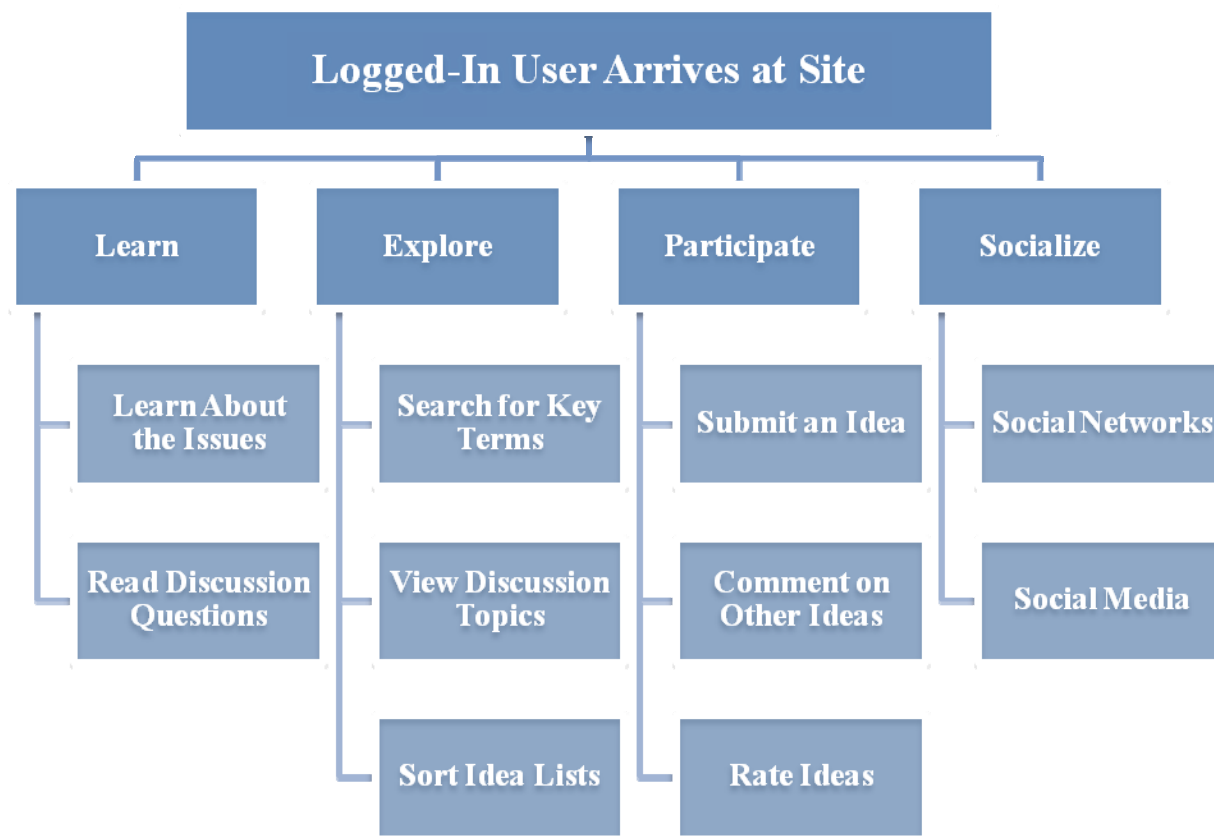Figure 2 represents the array of choices facing a user who has already logged into the site.

Figure 2: Available Activities for a Logged-In National Dialogue Participant

OUTREACH STRATEGY

Three outreach strategies were employed to recruit participation in the National Dialogue: Traditional outreach, e-mail outreach, and new media outreach.

Traditional Outreach

One element that distinguishes the National Dialogue process from a more traditional public advisory process is that participation is unconstrained by limitations of space or geography. Accordingly, the National Dialogue team pursued an outreach strategy that began with identifying broad groups of stakeholders whose voices would be relevant to a discussion of health care, IT and privacy. It then also used "viral" methods such as e-mail and newsletters, as well as "new media" venues such as third-party social media and social networking sites, to allow the discussion to grow organically and ensure that any interested and passionate citizen could participate whether or not they were part of an identified stakeholder group.

As with any public engagement in which participants are not pre-selected, this strategy did leave the National Dialogue susceptible to being overwhelmed by representatives of one particular

group or viewpoint, although both the substance of the Dialogue as well as sectoral metrics taken after the Dialogue[26] indicate that this did not occur. What was gained from this outreach strategy was a group of Dialogue participants that represented both traditional expertise and an original, more "grass-roots" approach to critical issues of health care, information technology, and privacy.

Groups and individuals initially identified as stakeholders fell into about seven broad categories, or "sectors":

- *Academia*—health and information schools; medical schools
- *Researchers*—universities and colleges; think tanks
- *Businesses*—large and small businesses that manage health care insurance for their employees; general information technology vendors
- *Consumers and Consumer Groups*—patients; patients' rights; privacy advocates; large membership organizations representing specific patient subgroups
- *Federal, State & Local Governments, Departments and Agencies*—U.S. Department of Health and Human Services; Centers for Disease Control; others
- *Health Care Professionals and Industry*—Insurance companies; hospitals; providers; health administrators; health information technology vendors; third party payers; large retail pharmacy chains
- *Open Government Advocates*

This list of sectors drove the traditional recruitment strategy. Participation goals were set for each sector: 33% consumer, disability and patient rights advocates; 33% health care professionals and industry representatives; 33% from government, business, open government advocacy organizations, researchers and academia.[27] Approximately 800 groups and individuals in these sectors were identified and contacted by the National Dialogue outreach team.

Outreach contacts were e-mailed a description of the event and invitation to talk on the phone, followed by a phone call, regardless of whether they responded. On the initial phone call, these contacts were invited to (1) participate, (2) spread the word to their network(s), (3) recommend five other people who should be invited, and if appropriate (4) serve as an advisor to the project.

Follow-up communication with interested parties encouraged them to share this opportunity with their professional networks. Contacts received tools to help them undertake their own outreach efforts, such as sample blog posts, invitation e-mails to forward, and newsletter announcements. Outreach to new and existing partner organizations continued throughout the week of the Dialogue, with targeted notices and reminders distributed to contacts.

A majority (58%) of the traffic to the website was direct, meaning that it was not referred by search engines or links on other websites. The primary explanation for that traffic is referrals from e-mails passed along by these contacts.

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[26] See the following section, "Traffic and Participation Metrics."

[27] Participants in the Dialogue were required to disclose which of these "sectors" they represented. See the following section for quantitative results in terms of sectoral participation.

E-Mail Outreach

E-mail was a critical tool in the outreach efforts for the National Dialogue. Hundreds of e-mails were sent by the outreach team in advance of the dialogue, informing recipients of the upcoming event and encouraging others to spread the word. During the event, eleven e-mail blasts were sent to participants and contacts in order to boost participation:

Description	Date	#	Audience
1 Week before - tell friends about project, visit our Facebook and Twitter pages	Oct 20, 2008	165	pre-registrants
Please repost your pre-registration comment on the live site.	Oct 27, 2008	47	pre-registrants (best ideas were selected to populate the site early with interesting posts)
Thanks for agreeing to forward this invitation to your network.	Oct 27, 2008	70	VIP contacts
Please forward this invitation to your network.	Oct 27, 2008	415	non-VIP contacts
Midweek update on the dialogue's hot ideas. Add yours, rate, and comment.	Oct 29, 2008	223	registrants
Reminder about timeline, plus e-mail to forward to others.	Oct 29, 2008	37	non-registrants
Last notice: Don't miss out. Featuring: hot topics in the dialogue, reminder about the resulting report.	Oct 30, 2008	386	cold contacts
Help rate ideas. Featured hot topics, newest ideas.	Oct 31, 2008	340	registrants & good contacts
Request to post and invite others from this sector.	Nov 3, 2008	52	consumer advocate and individual registrants (to avoid possible sectoral imbalance)
Rate a post, invite colleagues.	Nov 3, 2008	314	registrants
Last chance to participate, ask 5 friends to participate.	Nov 3, 2008	37	non-registrants

Table 1: Description of E-Mail Blasts Sent Before and During the National Dialogue

After the close of the Dialogue, thank-you e-mails were sent to participants. Participants also received a notice upon the publication of this report.

New Media Outreach

In addition to targeting a wide cross-section of individuals and groups, the National Dialogue team also pursued an aggressive recruitment strategy by leveraging new media formats such as blogs and social networks. This approach was intended to raise awareness of the Dialogue with leading voices on relevant issues and to encourage them to promote and report on the Dialogue in ways that were tailored and authentic to the communities they informed. The ultimate goal was to ensure that awareness of the initiative was both deep among targeted populations and wide across the population as a whole.

The outreach team identified and contacted 134 bloggers in the following categories:

Blog Category	Contacts Made
Doctor/Nurse	10
Patient	8
Consumer	7
Health IT	41
Government	9
Pharmaceutical	5
Seniors	5
Participatory Democracy	13
Websites	5
Doctor/Nurse	10
Patient	8

Table 2: Types and Numbers of Blogs Contacted for National Dialogue Outreach Strategy

The following are three examples of blogs who linked to thenationaldialogue.org:

The Health Care Blog by THCB (http://www.thehealthcareblog.com)
"...gather feedback from the public on the important privacy issues that confront all of us as we promote the movement to e-health. A report will be generated based on the responses, so it is important that a broad range of stakeholders participate. Go to http://www.thenationaldialogue.org to find out more and to log on!"

The National Dialogue in ICMCC Newspage (http://blogs.healthcare.com/icmcc)
"This is your chance to send a strong message to the next Administration about what our health IT and privacy policies should look like. Share your ideas, discuss them with others, and vote on the best ones. Make sure your voice is heard!"

National Dialogue on Health IT and Privacy in Tech Policy Central
(http://www.techpolicycentral.com)
"...A panel of Academy fellows will then use that feedback to create a report for federal agencies and the new Administration. Even if you don't have strong opinions on health IT, it's worth checking out the site to see how the Internet is being used to change the way citizens interact with the government. The dialogue will be underway through November 3rd"

Search engine ads were initially purchased, but the relevant keywords proved to be highly expensive per click and the effort was discontinued.

Paid advertising on blogs and search engines was also utilized. The results from blog advertising were 3,874,772 impressions (views) leading to 765 clicks through to thenationaldialogue.org. The average click through rate was 0.04%. The best performing blogs were tech blogs, followed by doctor blogs and then government policy blogs.

TRAFFIC AND PARTICIPATION RESULTS

Bringing together a large volume of participants who might not otherwise have the opportunity to find and discuss their differences of opinion is essential to the concept of a National Dialogue. This particular Dialogue pilot was not a representative sample of the American people. A sufficient volume, breadth and depth of participation would be required to ensure that the concerns and priorities of those who do participate more closely represent the broad community of citizens and stakeholders. However, several types of metrics give a good indication of the quantity of participation that this Dialogue pilot received, as well as some qualitative descriptions of that group in the aggregate.

Site Traffic

The most basic measure of engagement with the National Dialogue pilot is simple site traffic. While this metric does not reveal who participated in the Dialogue in terms of contributing content, it does reveal the relative success of outreach efforts in terms of both volume and geographic diversity. The National Academy used free Google Analytics software to track traffic on the site.

Over the course of eight days, the National Dialogue site, www.thenationaldialogue.org, received:
- 4,413 visits from 2,835 unique visitors, with the average visitor spending nearly eight minutes (7:54) on the site.
- 31,982 page views, with the average visitor looking at between 7 and 8 pages.
- A "bounce rate" of 38.55%, indicating the "percentage of single-page visits or visits in which the person left [the] site from the entrance (landing) page."[28]

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[28] "What does Bounce Rate mean?" Google Analytics.
<http://www.google.com/support/analytics/bin/answer.py?hl=en&answer=81986> November 19, 2008.

- At least two visits from every U.S. state and territory, with the most visits coming from the District of Columbia (464 visits), Maryland (415 visits), California (371 visits), and Virginia (343 visits) and the fewest coming from Wyoming, North Dakota, and South Dakota, with two visits each.
- Visits from 79 foreign nations, including the United Kingdom, Canada, Germany, India, Brazil, and Spain.

The "Digital Divide"

One of the most pertinent concerns facing the National Dialogue pilot was the so-called "digital divide," the gap between those citizens who have access to technology such as computers and the Internet, and those who do not. It is also the gap between those who choose to participate in this type of use of the technology and those who don't. The divide is particularly pertinent to the subject matter of health information technology and privacy, as areas with the least access to the Internet, and thus the least ability to participate in initiatives like the National Dialogue, are also in many cases the least likely to be able to take advantage of innovative information technologies in the realm of health care. This will need to be addressed in future Dialogues.

Participation from Urban, Suburban, and Rural Communities

While the "digital divide" was clearly a limiting factor on participation, it is also the case that one aspect of this divide is the gap in access to the Internet between urban and rural areas. As recently as May 2006, the U.S. Government Accountability Office found that:

> Households residing in rural areas were less likely to subscribe to broadband service than were households residing in suburban and urban areas. Seventeen percent of rural households subscribe to broadband service, while 28 percent of suburban and 29 percent of urban households subscribe to broadband service.[29]

While there is no way to measure what percentage of citizens who generally lack access to technology participated in this National Dialogue -- and indeed, this percentage would probably be low—analytics reviewed after the conclusion of the Dialogue indicate that the initiative gained participation from rural and suburban as well as urban areas.

For example, 161 visits to the National Dialogue site came from the state of Pennsylvania. The bulk of these came from the urban centers of Philadelphia and Pittsburgh, with 23 and 12 visits to the site, respectively. However, the site also attracted visits from many of the suburban and rural centers throughout the central portion of the state, including:
- Bryn Athyn, PA: 36 visits; pop. 1,351
- Dallastown, PA: 4 visits; pop. 4,087
- Flourtown, PA: 4 visits; pop. 4,669
- Conshohocken, PA: 3 visits; pop. 7,589

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[29] U.S. Government Accountability Office. *Telecommunications: Broadband Deployment Is Extensive throughout the United States, but It Is Difficult to Assess the Extent of Deployment Gaps in Rural Areas.* GAO.gov. May 5, 2006. <http://gao.gov/products/GAO-06-426>

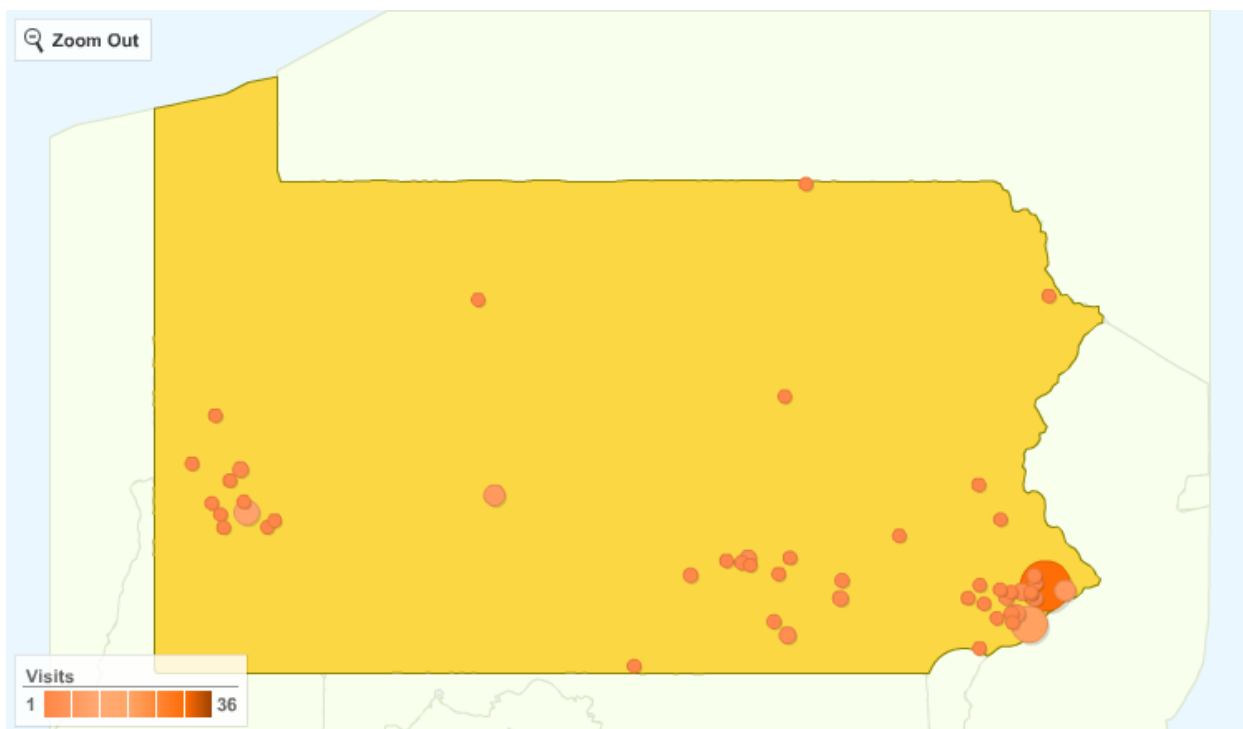This pattern is demonstrated visually in figure 3 below.

Figure 3: National Dialogue Participation in the State of Pennsylvania (Source: Google Analytics)

A similar pattern of distribution between urban, suburban, and rural centers was characteristic of overall participation in the Dialogue, and indicates that the initiative reached citizens from a wide array of communities. This, in turn, reinforces the potential and challenges of initiatives like the National Dialogue to engage citizens and stakeholders in a policymaking process from which they may otherwise be absent due to constraints of geography and proximity to political centers.

Participation Metrics

While traffic metrics are important in quantifying the reach of the overall National Dialogue pilot effort, metrics relating specifically to participation help to characterize the extent to which visitors were compelled to participate in the Dialogue.

Over the course of a week, the National Dialogue generated:
- 420 registered users, or about 14.8 percent of unique visitors
- 120 unique ideas, concerns, stories and principles
- 500 comments within discussion threads

Sectoral Metrics

As discussed earlier, participants were grouped into three sectoral categories in order to guide an outreach process that would incorporate a wide range of perspectives on issues of health, IT, and

privacy. These three categories were consumers, health professionals and industry and other (government, business, open government advocates and academics). The following table illustrates the breakdown of participants according to sector.

Metric	Consumer	Health	Gov	Business	Open Gov	Academia	TOTAL
% Goal	33%	33%	8.5%	8.5%	8.5%	8.5%	**100%**
Outreach (%)	25%	33%	9%	15%	6%	7%	**100%**
Participation	126	164	30	26	3	22	**371**
Participation (%)	34%	44%	8%	7%	1%	6%	**100%**

Table 3: Participation in the National Dialogue by Sector, As Identified By Registered Users

Demographic Metrics

In addition to specifying a "sector," participants in the National Dialogue were asked to submit the following optional demographic information:

- Age
- Gender
- Zip Code

Two important caveats apply. First, because submitting the data was optional, it is not possible to draw conclusions about the composition of the participant group as a whole. The number of respondents filling out these fields was 39% (age), 70% (gender), and 59% (zip code), respectively. Second, whatever conclusions can be drawn from this data should not be generalized to suggest that the participant group in the National Dialogue is reflective of the population as a whole. These statistics simply provide a way of characterizing the diversity of voices that did participate in the Dialogue.

The charts and graphics on the following pages illustrate the demographic breakdown according to information supplied voluntarily by some Dialogue participants:

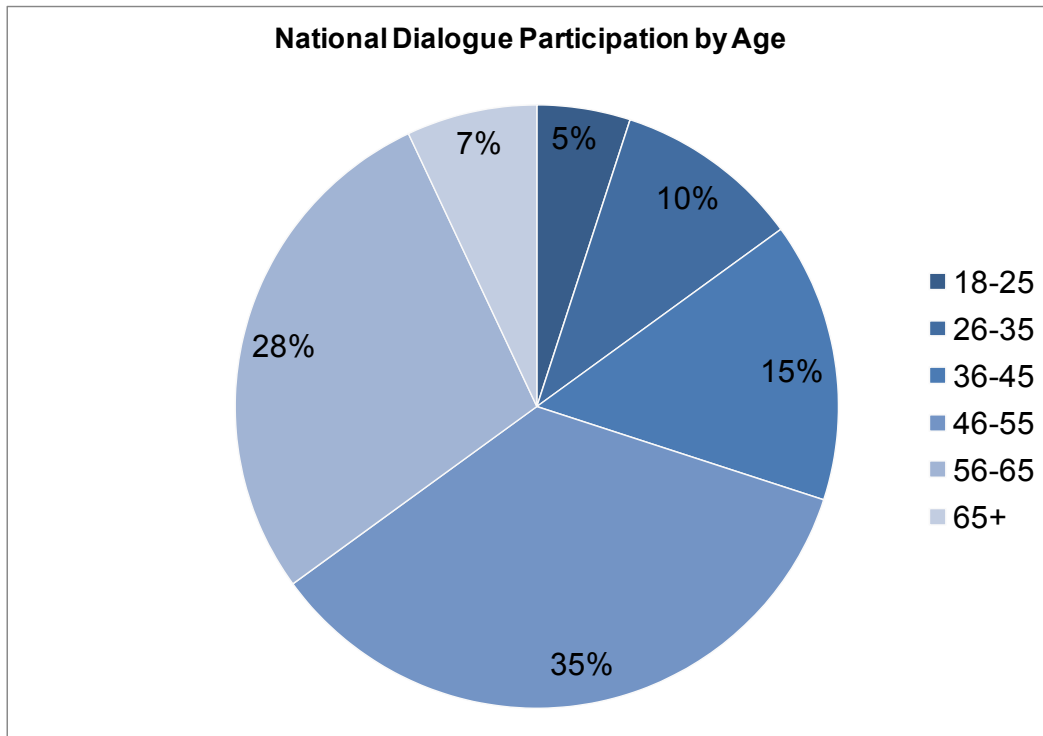**National Dialogue Participation by Age**

Figure 4: **National Dialogue Participation by Age (Source: Google Analytics)**

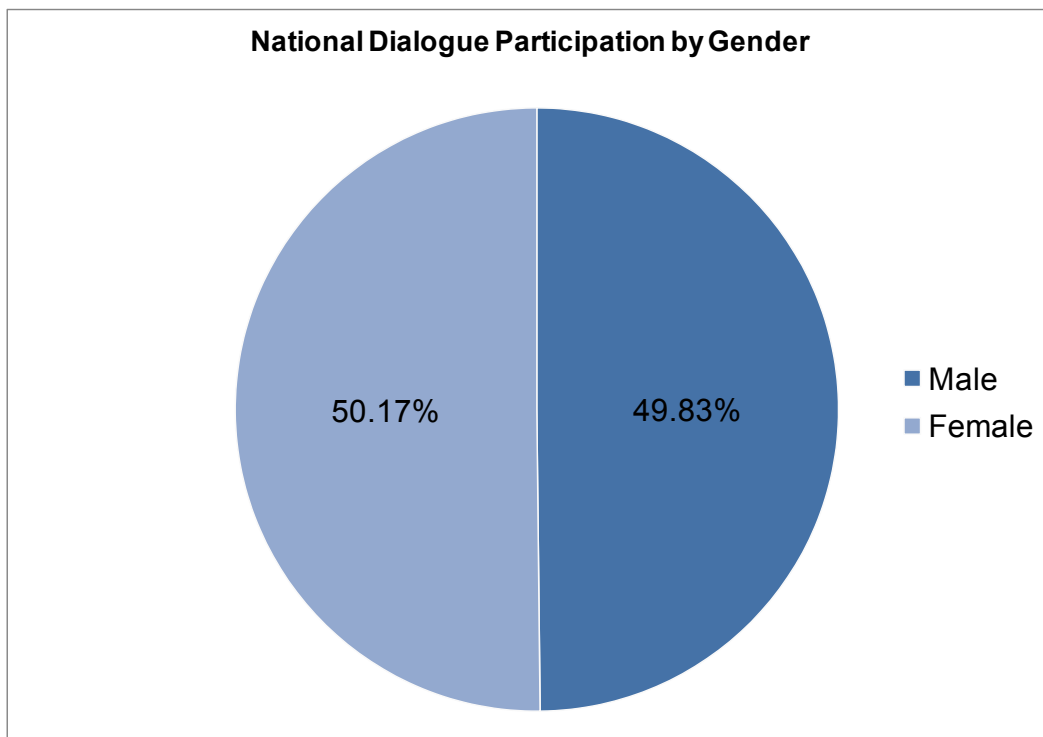**National Dialogue Participation by Gender**

Figure 5: **National Dialogue Participation by Gender (Source: Google Analytics)**

Figure 6: National Dialogue Participation by Zip Code (Source: Batchgeocode.com/Yahoo! Maps)

Social Networks

As noted earlier, the use of social networks was one critical element of the National Academy's strategy of recruiting Dialogue participants in a way that is organic and authentic to the relevant communities represented in the discussion. For this effort, a number of popular social networks were utilized for outreach and recruitment purposes:

- *Twitter*—Throughout the week, the popular microblogging service was used to provide brief updates on the Dialogue, recognize and communicate with other Twitter members who were focused on similar topics, and use the site's "Follow" functionality to discover new avenues for outreach efforts. (Many Twitter users utilize the service as a companion to a personal or professional blog.) The National Dialogue's Twitter feed, available at http://twitter.com/natldialogue, has posted 49 updates and attracted 183 Followers.

- *YouTube*—YouTube provided an optimal channel for raising awareness and knowledge of both the Dialogue itself and issues of health IT and privacy. Moreover, by providing users with one-click access to share videos on MySpace, Facebook, Digg, and other popular social networks, the YouTube medium provided viewers with an easy tool to invite others into the Dialogue. The National Academy produced two brief video segments: One explaining the National Dialogue effort, and another providing an overview of the potential benefits of health IT and the importance of privacy concerns. Together, these videos were viewed 529 times. They are available at http://www.youtube.com/user/natldialogue.

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- ***Facebook***—Using the social networking site's "Events" functionality, the project outreach team was able to invite Facebook members to join the National Dialogue, as well as allow invitation recipients to spread the word to others. Facebook also helped target a younger demographic than traditional outreach efforts, including a voice in the Dialogue that is often missing from debates about these issues. By the end of the week, the event had attracted 50 "confirmed guests," with invitations reaching an additional 286 Facebook members. Referrals from Facebook accounted for 1.5% of site traffic. The Facebook invitation remains publicly viewable at http://www.facebook.com/event.php?eid=30905107247.

- ***Digg***—The social bookmarking site provided a quick way for Dialogue moderators to highlight important links and allow others to promote them. Although this module did not provide a great deal of activity—in all, 8 links received only 11 "diggs"—it was a useful tool in featuring external sources of information about the Dialogue, such as blog posts by the American Academy of Family Physicians[30] and the Lyndon B. Johnson Presidential Library[31], and build credibility with users by showcasing this "earned new media" to Dialogue participants. The National Dialogue's Digg profile is available at http://digg.com/users/natldialogue.

- ***GovLoop***—GovLoop is a social network developed by a federal government employee, and aimed primarily at connecting others in the federal community. It is based on a service provided by Ning.com that allows individual citizens to build customized social networking sites. The National Academy used this platform to advertise the National Dialogue to potential participants through the site's "Blog" and "Events" modules, available at http://www.govloop.com/profiles/blogs/1154385:BlogPost:99741 and http://www.govloop.com/events/event/show?id=1154385:Event:99458, respectively. Response to these postings was not tracked.

- ***OpinionTracker***—OpinionTracker is a tool developed by Delib that "monitors what people are thinking and saying around the Internet…[it] track[s] conversations around the net (in forums, in blogs and in videos) and then analyze[s] these to show what people are thinking and saying about specific issues."[32] An OpinionTracker set to monitor topics of health IT and privacy was created and deployed on the National Dialogue site itself, providing users with a way to both learn more about the issue and connect with others who were discussing it. Over the course of the Dialogue, the site tracked 501 blog entries,

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[30] "Join Online Discussion on Health IT." AAFP News Now. <http://www.aafp.org/online/en/home/publications/news/news-now/practice-management/20081028healthitonline.html> October 28, 2008

[31] Willingham, Taylor. "The online National Dialogue on Health Information Technology and Privacy is LIVE!" Texas Forums. <http://texasforums.wordpress.com/2008/10/27/the-online-national-dialogue-on-health-information-technology-and-privacy-is-live/> October 27, 2008.

[32] "OpinionTracker: London Mayoral Elections '08: About OpinionTracker." OpinionTracker. <http://www.opinion-tracker.co.uk/london_mayoral_election_08/public/about_opinion_tracker> December 10, 2008.

Twitter posts, and other pieces of content. This material can be found at http://www.thenationaldialogue.org/healthit/opiniontracker/.

While these social networks were powerful tools for increasing interest and participation in the National Dialogue, there are still a relatively limited number of people who use these networks on a regular basis. In the future, there will be a need to find more channels to gain the needed volume, depth and breadth of input.

APPENDIX A: PANEL AND STAFF BIOGRAPHIES

PANEL

Franklin S. Reeder,[*] *Chair*—President, The Reeder Group. Former Director, Office of Administration, The White House. Former positions with U.S. Office of Management and Budget: Deputy Associate Director for Veterans Affairs and Personnel; Assistant Director for General Management and Deputy Assistant Director; Chief, Deputy Chief, Information Policy Branch; Policy Analyst; Chief, Systems Development Branch. Former Deputy Director, House Information Systems, Committee Staff, Committee on House Administration, U.S. House of Representatives. Former positions with U.S. Department of the Treasury and U.S. Department of Defense focusing on information technology and systems.

Alan P. Balutis[*]—Former President and Chief Executive Officer, INPUT; President and Chief Operating Officer, Veridyne Inc.; Deputy Chief Information Officer, U.S. Department of Commerce. Former positions with the U.S. Department of Commerce: Director, Office of Budget, Management, and Information; Acting Chief Information Officer; Director, Budget, Planning, and Organization; Director, Office of Management and Organization; Director, Office of Systems and Special Projects; Chief, Policy and System Staff; Senior Analyst, Office of Program Evaluation. Increasingly responsible positions with the U.S. Department of Health, Education, and Welfare in the areas of budget, personnel, policy, and legislation, management.

Gary A. Christopherson[*]—Founder, viaFuture. Former Senior Advisor to the Chief Operating Officer, Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services; Senior Advisor to the Under Secretary of Health and VHA Chief Information Officer, U.S. Department of Veterans Administration; Deputy Director, Quality Improvement Group, Centers for Medicare and Medicaid Services; Acting Assistant Secretary and Principal Deputy Assistant Secretary of Defense for Health Affairs, U.S. Department of Defense; Associate Director, Office of Presidential Personnel, The White House. Sculptor.

C. Alan Lyles[*]—Co-Section Editor of Pharmaceutical Economics and Health Policy, for Clinical Therapeutics. Chaired the Association of American Medical Colleges' Group on Institutional Planning, the American Public Health Association Medical Care Section's Drug Policy and Pharmacy Services group, and the Maryland State Drug Utilization Review Board. Served as an external reviewer for the Government Accounting Office (GAO); and has given a multi-day training course at the US Food and Drug Administration, sponsored by its Office of Drug Safety. Direct experience health services management experience includes administrative work as Assistant Dean for Planning and Analysis at the Johns Hopkins University School of Medicine (1990s); administrator of a clinical department at The Johns Hopkins University School of Medicine (1980s); and General Manager of Johns Hopkins Hospital's Outpatient Department (1970s).

Sallyanne Payton[*]—William W. Cook Professor of Law, University of Michigan School of Law. Former Associate Professor, University of Michigan School of Law; Chief Counsel, Urban Mass Transportation Administration, U.S. Department of Transportation; Staff Assistant to the President of the United States, Domestic Council, The White House; Attorney, Covington & Burling; Chair, Administrative Law Section, Association of American Law Schools (2001-02); Public Member and Senior Fellow, Administrative Conference of the United States (1976-94); Consultant, President's Commission on National Health Care Reform (1993).

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[*]   *National Academy Fellow*

STAFF

Frank DiGiammarino, *Vice President for Strategic Initiatives and Business Development*—Frank DiGiammarino oversees business development and the creation and execution of special initiatives at the National Academy that can deliver innovative approaches to addressing government's management challenges. In addition, he oversees the National Academy's government relations, outreach, and communications efforts. Frank has previously served as a Program Area Director and Director of the National Academy's Executive Consortium. He has also worked on National Academy studies of the Federal Bureau of Investigation, with a specific focus on field structure reorganization. Former positions include: Director and DoD Practice Area lead, Touchstone Consulting Group; General Manager and Director of Program Management, Sapient Corporation; and Principal Consultant with the State and Local Practice, American Management Systems.

Lena E. Trudeau, *Program Area Director*—Lena Trudeau oversees the National Academy's work with the U.S. Coast Guard, the Federal Emergency Management Agency, the Environmental Protection Agency, the Department of State, and the National Park Service. In addition, Ms. Trudeau directs the Collaboration Project, an independent forum of leaders committed to leveraging Web 2.0 and the benefits of collaborative technology to solve government's complex problems. Immediately prior to joining the National Academy, she served as Vice President, Consulting Services for Ambit Group, a strategy and technology consulting firm dedicated to the federal marketplace. Previously, she has held positions at Nokia, the world leader in mobility, at Touchstone Consulting (now SRA, Inc.), and in the Privy Council Office of the Government of Canada. She holds a Masters of Business Administration.

Lois Fu, *Senior Advisor*—Lois Fu is a Senior Advisor to the President at the National Academy of Public Administration and a member of the executive management team. She also serves as a Program Area Director overseeing projects funded by foundation and corporate grants. Ms. Fu has served as a senior manager in a number of Federal agencies, including the Federal Transit Administration, Transportation Security Administration, and in the U.S. representative's office at the World Bank. Formerly, Ms. Fu served for 14 years in a variety of leadership positions at the American National Red Cross, including as a corporate officer and secretary to the National Board of Governors. She has also served as a legislative assistant to Senator John Glenn (D-Ohio) and as the staff director for the Senate Subcommittee on Aging.

Danielle Germain, *Project Director*—Danielle Germain is the Director of the National Academy's Collaboration Project. She has previously served as the Project Director for the National Dialogue on Health IT and Privacy. Her previous roles include: Director of Operations, American Council for Technology/Industry Advisory Council; Director of Technology Programs, Council for Excellence in Government; and Senior Program Manager, Information Technology Association of America. Ms. Germain has also served as a Congressional Aide to Senator Edward M. Kennedy (D-Mass.).

Bryna Helfer, *Senior Director of Civic Engagement*—Bryna Helfer is leading the execution phase of the National Academy's Big Game project, including outreach to universities and potential sponsors. Ms. Helfer has over 25 years of experience in initiating, leading, and facilitating interagency coordination, program development, program evaluation and strategic change initiatives. She has a long history of forging partnerships between governmental agencies and community-based organizations. Her Federal experience includes GAO and the Federal Transit Administration, where she led the Federal Interagency Coordinating Council on Access and Mobility. She has also served as director of the Traumatic Brain Injury Technical Assistance Center and Project ACTION.

Daniel A. Munz, *Senior Research Associate*—Daniel A. Munz is the Project Manager of the National Academy's Collaboration Project. He pas previously worked on National Academy studies of the U.S. Department of Energy, Federal Bureau of Investigation, and Department of Veterans Affairs. Previous

roles include: Director of Internet Communications, Norman Siegel for Public Advocate; Politics and Elections Aide, Citizens Union Foundation.

AmericaSpeaks

Joe Goldman, *Vice President of Citizen Engagement*—Mr. Goldman oversees the organization's citizen engagement initiatives to provide citizens with a greater voice in policy making. Mr. Goldman has directed several of the largest citizen engagement initiatives ever conducted in the nation, including a regional discussion in Northeast Ohio that involved more than 20,000 citizens, a statewide conversation on health care reform in California, and America*Speak*s' work to involve current and displaced residents of New Orleans in the creation of their city's recovery plan after Hurricane Katrina. Mr. Goldman is on the Board of Editors of the International Journal of Public Participation and has authored numerous articles on citizen engagement.

Susanna Haas Lyons, *Communication Manager & Program Associate*—Ms. Haas Lyons designs and manages projects by AmericaSpeaks to engage the public in governance. In addition, she manages AmericaSpeaks print and online publications and communications. Before joining AmericaSpeaks, Susanna served as project coordinator with the Citizens' Assembly on Electoral Reform. In addition, Susanna was the principle of a Vancouver-based citizen engagement consulting practice, working with government, private enterprise and non-profit groups.

Dianna Dauber, *Communications Coordinator*—Ms. Dauber supports the communications and project work at AmericaSpeaks, providing writing and outreach leadership. Previously, Ms. Dauber worked as a Publicity Associate for Buffalo Communications. She obtained her bachelor's degree from the George Washington University and has a master's degree in communications from Trinity University.

Delib

Ben Whitnall—Mr Whitnall leads Delib's strategic, planning and optimization work; this includes providing consultancy on client projects to improve their effectiveness for both the client and the end user. Mr Whitnall has worked on projects with the European Parliament, the UK's Department for Environment, Food and Rural Affairs, JANET, JISC and the Office of the Deputy Prime Minister.

Laura Wotherspoon, *Project Manager*—Ms. Wotherspoon is responsible for delivering Delib's online opinion research and public consultation projects on time, on budget and en accord with client expectations. Ms. Wotherspoon has done this on projects for several UK Central Government departments as well as the Joint Information Systems Committee and various UK local authorities. Ms. Wotherspoon's previous roles include: Production Co-ordinator, Carlson Digital; Commercial Producer, Sounds Visual Radio Production; Archaeologist, just for fun.

Alan Hoey, Jess Norwood, Anthony George, Matthew Wilkes, Owen Curtis-Quick, Lisa Rex, *Development team*—Whilst made up of many parts, the Delib development team functions as a single, unified, devastatingly effective entity. They have coded, skinned, tested and maintained sites and systems for clients like the BBC Trust, London Fire Brigade and several UK Central Government departments. Adam Abu-Nab, Jenny Hardy, Ally Stuart

Opinion trackers—Delib's committed band of Opinion Tracker editors and moderators are responsible for initiating, refining, checking, filtering and cleaning the Opinion Tracker system and the data it collects. They have tracked internet opinions on everything from the London Mayoral elections to major movie releases.

APPENDIX B: STEERING COMMITTEE & DISCUSSION CATALYSTS

STEERING COMMITTEE

Julie Beckett, *Family Voices*—Julie Beckett is the Policy Director and co-founder of Family Voices, a national grassroots organization of families and friends speaking on behalf of children with special health care needs and their families. In this role, Ms. Beckett has brought communities and families together to obtain services for children with special needs and disabilities. Her daughter is Katie Beckett, in whose name a Medicaid home and community-based waiver program was developed.

Phyllis Borzi, *The George Washington University*—Phyllis Borzi is a Research Professor in the Department of Health Policy at The George Washington University's School of Public Health and Health Services. Her work has focused on improving access to health care coverage, and prior to joining the faculty of George Washington, Professor Borzi worked on health issues as a counsel to the House Subcommittee on Labor-Management Relations. She currently practices law for the Washington law firm O'Donoghue & O'Donoghue, where she provides legal guidance on health, pension, and other employer-sponsored benefits plans.

Paul Cotton, *AARP*—Paul Cotton is Senior Legislative Representative for health issues for AARP's Federal Affairs Department. Prior to joining AARP, Mr. Cotton served as Director of Hearings and Policy Presentation at the Centers for Medicare and Medicaid Services in the U.S. Department of Health and Human Services. He also previously worked for the Journal of the American Medical Association and the Center for Medicare Advocacy, Inc.

Tina Grande, *Healthcare Leadership Council*—Tina Grande is the Senior Vice President for Policy for the Healthcare Leadership Council. Prior to her current position, Ms. Grande served as a health policy advisor to the law firm Arnold & Porter and co-founded Medicare Advisory Group, Inc., a San Francisco-based health care policy and technology company providing hospitals and long-term care facilities with a software solution to ease the complexity of managing Medicare regulations. Ms. Grande also previously served as a health policy analyst for Senator David Durenberger (R-Minn.) and for the law firm Patton Boggs.

Deven McGraw, *Center for Democracy and Technology*—Deven McGraw is the Director of the Health Privacy Project of the Center for Democracy and Technology (CDT), where she focuses on developing and promoting public policies that ensure individual privacy as personal health information is shared electronically. Prior to joining CDT, she was the Chief Operating Officer of the National Partnership for Women & Families and was an associate in the public policy group at Patton Boggs, LLP, and in the health care group at Ropes & Gray. Ms. McGraw also previously served as Deputy Legal Counsel to the Governor of Massachusetts.

Gregg Pane[*]**,** *U.S. Department of Health and Human Services*—Dr. Gregg Pane is a Fellow in the National Academy of Public Administration and is currently the Director of the National Health Care Preparedness Programs for the U.S. Department of Health and Human Services. Prior to this position, Dr. Pane served as the Director of the Department of Health for the District of Columbia, System Vice President for Clinical Quality and Public Policy at the Henry Ford Health System in Detroit, Michigan, and Chief Policy and Planning Officer for the U.S. Veterans Health Administration.

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[*] *National Academy Fellow*

Claudia Williams, The *Markle Foundation*—Claudia Williams is the Director of Health Policy and Public Affairs for the Markle Foundation, where she advances policy issues related to health information technology and information sharing in the evolving networked world. Before joining the Markle Foundation, Ms. Williams was the founder and principle of AZA Consulting and director of the Synthesis Project, an initiative of the Robert Wood Johnson Foundation. Ms. Williams also previously served as a senior policy analyst in the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services and as a Senior Manager at The Lewin Group.

DISCUSSION CATALYSTS

Julie Beckett, *Family Voices*
Phyllis Borzi, *The George Washington University*
Paul Cotton, *AARP*
Mark Gorden, *eHealth Initiative*
Tina Grande, *Healthcare Leadership Council*
Dr. David Kibbe, *American Academy of Family Physicians*
Deven McGraw, *Center for Democracy & Technology*
Dr. William A. Yasnoff, *Health Banking Alliance*

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