

August 5, 2008

via email

Re: letter of committment

Nebraska Information Technology Commission
501 South 14th Street, 4th Floor
Lincoln, NE 68509-5045

To Whom It May Concern:

The Board of Regents of the University of Nebraska, for the University of Nebraska-Lincoln (UNL) is pleased to submit a proposal to your organization on behalf of Tarik Abdel-Monem of the Public Policy Center, entitled "Public Input on Sharing Electronic Health Records: The Views of Nebraskans".

The total request is for \$20,800 for the proposed period October 1, 2008 thru February 28, 2009. Our EIN # 47-0049123 and our DUNS # is 55-545-6995. Our participation is administratively approved on behalf of the Board of Regents by the appropriate University officials, as evidenced by my signature as an authorized official on this letter of transmittal.

Questions regarding the technical aspects of this project should be directed to Dr. Abdel-Monem at (402)472-3147. Administrative questions should be directed to Nancy Becker, Grants Coordinator, at (402)472-3601 or nbecker1@unl.edu. We look forward to participating in this project.

Sincerely,



Suzan G. Lund
Associate Director

SL/nb

**Nebraska Information Technology Commission
Community Technology Fund**

Simple Application Form

For projects which meet all of the following characteristics:

- Low budget (under \$40,000)
- No or simple implementation of technology (By simple implementation of technology, we mean standard, plug and play technology.)
- Very low risk
- Type of projects: Training projects, HISPC legal review

Project Title: Public Input on Sharing Electronic Health Records: The Views of Nebraskans

Submitting Entity (Must be a public entity): Board of Regents, University of Nebraska on behalf of the University of Nebraska Public Policy Center

Grant Amount Requested: \$20,800.00

Project Contact Information (Name, address, telephone, and e-mail address):

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Executive Summary

Provide a one or two paragraph summary of the proposed project, clearly and succinctly describing the project goals, expected outcomes, the information technology required, and what the grant will fund.

The overall goal of the proposed project is to obtain perspectives of Nebraskans about electronic sharing of health information, and in particular, perspectives about legal and policy issues currently under consideration by the NITC, HISPC, e-Health council, and other state policymakers and advisory groups. The funds provided by the grant will support our activities to document Nebraskans' knowledge of and attitudes towards these issues by preparing for and convening two surveys and a Deliberative Poll®. Randomly selected residents of Nebraska from three communities across the state will be invited to participate in an online survey. Twenty five to thirty residents of Lincoln/Lancaster County will be invited to participate in the Deliberative Poll and take a second survey. The Public Policy Center will work closely with a stakeholders' working group composed of members of the NITC, HISPC, e-Health council, and others, to identify priority questions of interest that are either currently – or will soon be – under consideration by state policymakers, and which public input and commentary could shed light on. This project will simultaneously achieve three outcomes: It will 1) engage a sample of Nebraskans about important legal and policy issues surrounding e-sharing of health information; 2) increase knowledge and understanding of these issues among a sub-sample of Nebraskans; and 3) provide state policymakers and stakeholders with perspectives from the public about these important issues. The project completion date is December 2008, and all findings will be disseminated publicly prior to the January 2009 legislative session.

1. Describe the project and project goals. (10 points)

We propose to engage randomly selected Nebraskans about their perceptions of electronic sharing of personal health information. Specifically, we will gather both **quantitative and qualitative** data from residents through a public consultation process gauging their attitudes towards **current questions of legal and policy relevance** about e-sharing of health information. Working with a **stakeholders group**: members of the Nebraska Information Technology Commission (NITC), Nebraska Health Information Security and Privacy Committee (HISPC), e-Health council, and policymakers, our engagement activity will be designed to specifically solicit information from area residents that would be of benefit for state lawmakers.

Our public input process will be composed of two stages. **First**, we will administer an **online survey** to measure public knowledge of and attitudes towards e-sharing of health information, with an emphasis on gauging public perceptions about issues that may be considered by the state legislature or other administrative, consultative, or policymaking bodies. Participants will be selected from randomly generated lists of residents drawn from the Lincoln/Lancaster County area, Omaha, and a six county area surrounding Kearney.¹ **The survey questions will be developed with close consultation from our stakeholders group**, and in particular, the legal subcommittee of the HISPC. **Possible topics of interest might include** changing restrictions on releases of health information, handling of sensitive information such as HIV or mental health status, defining the acceptable parameters of exchanging personal health information between Regional Health Information Organizations, storage of health information records by private companies (i.e. Microsoft or Google), and other areas implicating possible changes in laws or regulations, as well as general questions assessing the public's current knowledge of and attitudes towards health information sharing. **Second**, we will convene a forum utilizing the **Deliberative Polling®** model to gather further input on legal and policy issues related to e-sharing of health data from Lincoln/Lancaster County respondents of the online survey. The Deliberative Poll will provide an opportunity for participants to discuss and deliberate these issues amongst themselves and with **a panel of experts** composed of representatives from the stakeholders group. The Deliberative Poll will provide an opportunity for the stakeholders group to **educate** participants about the issues, **present** them with the difficult policy questions they face, and **seek their input**.

Deliberative Polling is a novel method that has been employed in recent years by government entities to much success.² Unlike traditional notice and comment proceedings, public hearings, or telephone surveys standing alone, Deliberative Polling combines random sampling with deliberative discussions as a means to measure attitudes and knowledge about policy issues among an informed and representative sample of participants. Deliberative Polls were first conducted in the United States in 1996, but have since been convened in Australia, Britain, China, Denmark, Greece, Italy, Northern Ireland, and various other nations.³

In the Deliberative Polling model, a **survey** (survey 1) is conducted of a **random sample** of individuals about the public policy issue(s) of interest. That sample is then provided with educational **background materials** about the issues of interest, and then invited to participate in small group deliberations and engage a panel of experts in a question-and-answer period. A **follow-up survey** (survey 2) of the sample is then conducted which measures the extent to which the deliberative process altered opinions or knowledge of the issue(s) of interest. Deliberative Polling provides an opportunity for participants to discuss their viewpoints with others and learn

¹ We will invite up to 450 randomly selected residents of Nebraska to participate in the survey. We expect a response rate of anywhere from 15%-25%.

² See James F. Fishkin, Center for Deliberative Democracy, Stanford University, *Deliberative Polling®: Toward a Better-Informed Democracy*, available at <http://cdd.stanford.edu/polls/docs/summary/>.

³ See Center for Deliberative Democracy, Stanford University, <http://cdd.stanford.edu/>.

more about the topic(s) of interest. A Deliberative Poll thus **measures changes in knowledge and attitudes** towards the topic(s) of interest among a random sample of individuals who have become more informed about an issue. Because participants are drawn from a random sample of the public, a Deliberative Poll indicates what the general population would conclude (within a margin of error) about an issue if it were to learn more about the issue and had a chance to discuss it. More information about Deliberative Polling can be found at the website of the Center for Deliberative Democracy at Stanford University (<http://cdd.stanford.edu/>).

We will convene one Deliberative Poll in Lincoln, with 25-30 randomly selected residents of the **Lincoln/Lancaster County** area. Although the small size of this sample will place constraints on generalizing any results from the discussion to other communities, it will serve to provide insight into what ordinary individuals know of and think about these issues. **We will invite members of the NITC, HISPC, the e-Health council, and policymakers to serve as expert panelists and observers** at the deliberation itself, as well as provide guidance as to the content of the discussion and overall project development. In addition to surveys, qualitative data will be gathered from the deliberative discussions through audio-recordings, which will be transcribed and analyzed. Working with this stakeholders group, we will generate a **background document** about current legal and policy issues facing the state that will be disseminated to the participants prior to the Deliberative Poll. We will also make this document available on our website as an **educational tool** for wider consumption by the public.

Public Input Process
Step 1. Randomly selected residents will be invited to participate in an online survey (survey 1). Hard copies will be available upon request. Residents will be from Lincoln/Lancaster County, Omaha, and a six county area surrounding Kearney.
Step 2. 25-30 Lincoln/Lancaster County area respondents from survey 1 will be invited to attend the Deliberative Poll in Lincoln. Deliberative Poll discussions will be audio-taped.
Step 3. Survey 2 will be administered following the Deliberative Poll.

The project specific goals we will accomplish include:

- **Documenting knowledge of and attitudes towards** e-sharing of health records among members of the public using both surveys and discussions;
- **Engaging stakeholder partners** such as the NITC, HISPC, the e-Health council, and policymakers, in an interactive discussion with members of the public through a Deliberative Poll;
- **Analyzing perceptions of important legal and policy questions** related to e-sharing of health records from the public's perspective.

2. Describe the project team and project activities. (10 points)

The Public Policy Center is well-equipped to implement this assessment of public opinion and knowledge. **Public participation is one of the Policy Center's five strategic areas of research.** Since 2004, the Center has convened eight deliberative discussions – primarily in partnership with NETV and PBS's McNeil/Lehrer Productions – in communities across Nebraska on topics ranging from public perceptions of genetically modified foods to K-12 public education in rural areas. Most recently, the Center coordinated the City of Lincoln's five-prong public

participation initiative regarding budget priorities for 2008-09 that involved collecting a variety of input from Lincoln residents: 1) a telephone survey of 600+ randomly-selected sample of residents; 2) a deliberative discussion involving 51 residents; 3) a non-random sample survey, available online and in hard copy, that was taken by over 1,500 residents; 4) four town hall meetings (convened and coordinated by Leadership Lincoln); and, 5) a focus group discussion.

The Policy Center will identify a **stakeholders group** of representatives from the NITC, HISPC, the e-Health council, and policymakers to serve as project consultants, as well as expert panelists at the Deliberative Poll. Development of our survey instruments and background educational document will be facilitated by active consultation with this stakeholders group.

Tarik Abdel-Monem is the PI for the project. He will be responsible for daily management of the project and specific project tasks including development of survey materials and the background document, recruitment of participants, and management of the Deliberative Poll. He also will be the project's liaison with the working group. Abdel-Monem has coordinated or co-coordinated eight deliberative discussions in Nebraska on a wide range of topics, including foreign policy (2004), globalization (2004), future community development of Lincoln (2005), consumption and labeling of genetically modified foods (2005), K-12 education in Nebraska (2005), water management in Nebraska (2006), immigration issues (2007), and outcomes-based budgeting for the City of Lincoln (2008). Abdel-Monem's responsibilities have included managing recruitment of participants, training project staff, developing educational materials and survey tools, administering deliberative activities, coordinating with community and academic partners, and serving as a liaison with affiliated media partners.

Alan Tomkins will work with PI Abdel-Monem. Tomkins will assist Abdel-Monem with project visioning and will serve as the described above. He has directed the University of Nebraska Public Policy Center for 10 years. Prior to being selected as the Center's founding director in 1998, Tomkins was a professor in the Law-Psychology Program at the University of Nebraska-Lincoln. From August 2005-July 2006, he was one of two inaugural William J. Clinton Distinguished Fellows at the University of Arkansas School of Public Service. He is a Fellow of the American-Psychology Law Society (Division 41 of the American Psychological Association) and the Society for the Psychological Study of Social Issues (Division 9 of the American Psychological Association). Tomkins serves as Co-Editor of *Court Review: The Journal of the American Judges Association*, working with Editor Judge Steve Leben of the Kansas Court of Appeals. Tomkins is the first non-judge to serve as an editor of *Court Review*. His primary research interests include public participation and its implications for democracy in policymaking, and public trust and confidence in government and other institutions.

Both Abdel-Monem and Tomkins were part of the Center's team that evaluated the CDC's Public Engagement Pilot Project on Pandemic Influenza that included public input from residents in four cities in four different states across the country (see http://ppc.nebraska.edu/publications/documents/PEPPPI_FINALREPORT_DEC_2005.pdf). The triangulation of quantitative and qualitative data revealed that the public felt pleased about their involvement and increased their knowledge about pandemics and vaccination policies during the process. As one stakeholder noted, "I still have the same opinions, but it clarified them a bit about why I feel this way." Anecdotal evidence indicates that US HHS Secretary Leavitt was aware of the project and its results, and used the information from the project as part of his input when President G.W. Bush held a table-top exercise on pandemic influenza for his Cabinet.

3. Describe the expected outcomes and benefits. (30 points)

As technology continues to evolve, e-sharing of health data has enormous potential for improving health care and reducing health care costs. For the general public, however, the notion that their individual health records be shared electronically raises a number of concerns – some

unfounded, some not—about privacy, accuracy, employer-employee relations, and other issues.⁴ Many lay members of the public know little about the current state of electronic health data sharing, and what its potential advantages, and potential disadvantages, are. This dearth in public understanding could alter or delay industry and/or government efforts to expand electronic sharing of health data. **For these reasons, it is important that policymakers engage members of the public and understand what their knowledge and attitudes are of electronic health data sharing.**⁵

Public participation in policymaking is important for a number of interrelated reasons. Understanding the public's views can help in **fashioning effective policies and practices** that are compatible with public beliefs and expectations. Understanding public views can also provide guidance about **developing educational strategies** if it is found there are public misunderstandings that can be addressed via appropriate information. Additionally, ordinary people have **opportunities to learn what challenges and trade-offs** policymakers face when it comes to important issues. Moreover, public participation comports with people's sense of **fairness and procedural justice**. Research has clearly shown that when people feel they have been treated fairly, they are more likely to report feeling positive about decision-making processes and outcomes, even if those outcomes are adverse to their own interests.⁶ In other words, they are more likely to support government actions in which they have had an opportunity to provide input. In short, **public participation enables policymakers to make informed decisions with input from people their policies might impact.**

This project will achieve the **following outcomes** - We will:

- 1) **Engage a randomly selected group of Nebraskans** about e-sharing of health information vis-à-vis a survey(s) and Deliberative Poll;
- 2) **Increase knowledge and understanding** of the issues surrounding e-sharing of health data, and the key legal and policy questions currently facing state policymakers;
- 3) **Provide Nebraska's policymakers with meaningful quantitative and qualitative input** from a segment of the public about these issues.

Essentially, this project is intended to **enhance the state's capacity to adequately address questions of legal and policy relevance surrounding e-sharing of health data** by providing a sample of Nebraskans with an opportunity to consider these issues, and inform **policymakers about their perspectives.**

We expect that at baseline, our sample of residents may not know much about the mechanics of e-sharing of health data, nor have well-informed opinions about some of the legal and policy relevant questions of interest to stakeholder groups like the NITC or HISPC. We also expect that many of these Nebraskans may share the same reservations about privacy and security implications that Americans in general have about electronic data sharing of personal information.

⁴ E.g., Shreema Mehta. (2006, July 25). Electronic patient data system raises privacy concerns. *The New Standard*. Available on –line at <http://newstandardnews.net/content/index.cfm/items/3456>; Alan F. Westin. (2005, February). Public attitudes toward electronic health records. *Privacy and American Business*, 12(2), pp. 1-5.

⁵ E.g., Remarks of Dan Rode, vice president of policy and government relations, American Health Information Management Association, at the 2003 meeting of the National Health Information Infrastructure, US Health & Human Services, Privacy Track, Slide 14. Available at <http://aspe.hhs.gov/sp/NHII/Conference03/PrivacyAB.pdf>.

⁶ See Amy Gangl, *Procedural Justice Theory and Evaluations of the Lawmaking Process*, 25 Political Behavior 119-149 (2003); Jeffery Mondak, *Institutional Legitimacy and Procedural Justice: Reexamining the Question of Causality*, 27 Law & Society Review 599-608 (1993); Tom Tyler, *Governing Amid Diversity: The Effect of Fair Decision Making Procedures on the Legitimacy of Government*, 28 Law & Society Review 809–831 (1994).

However, we also expect to see a gain in knowledge and change in attitudes toward the legal and policy issues surrounding e-sharing. In our experience with other deliberative discussions, there have been significant changes in knowledge and attitudes about a variety of public policy issues after members of the public have an opportunity to learn about and discuss them.⁷

The **primary product** from the project will be a Final Report that synthesizes the results from the Deliberative Poll, both the quantitative data (surveys 1 and 2) and qualitative data (transcriptions of audio-recorded deliberations). The Final Report will be issued to the funders, and made available to policymakers and the public via the Public Policy Center's website. **The Final Report will be written prior to the beginning of the legislative session in January 2009.** The **beneficiaries** of the project will be those with interests in electronic health records, and particularly questions of legal and policy relevance currently under consideration: I.E. the public; policymakers; policymaking or consultative bodies like the NITC, HISPC, and e-Health council; and health care and information technology professionals in general.

4. List the major activities (or milestones) and a timeline for completing each activity or milestone. (10 points)

- Week 1: Preparation (identification of working group and other stakeholders)
- NITC and PPC agree on working group membership
 - Invitations issued to working group membership
- Weeks 1-4: Development of survey instruments and briefing document
- Meetings established with working group
 - Surveys and briefing document approved by working group
 - Date for deliberation determined
 - Expert panelists identified
- Weeks 5-6: Recruitment of participants and Implementation of survey 1
- Final plans for deliberation approved
- Weeks 6-7: Hold deliberation discussions and implement survey 2
- Hold debriefing session with working group after deliberation and finalize dissemination strategies
- Weeks 7-8: Analyze findings
- Review results and implications with working group
- Week 10: Issue final report
- Implement report distribution plan and other dissemination strategies

5. Describe how the project will be sustained. (10 points)

This project is a one-time set of activities intended to gather information from the public that will provide insight about current issues of legal and policy relevance related to e-sharing of health data. We will synthesize all quantitative and qualitative data into the Final Report, which will be issued to the NITC and other stakeholders prior to the opening of the 2009 legislative session.

It is nonetheless the case that the public participation processes used in the proposed project will be useful for the NITC when it confronts policy questions in the future that benefit from the public's input. In that sense, the proposed project can be seen as a proof of concept, and once the benefits of the public input approaches proposed here are demonstrated to the NITC, these

⁷ To access reports of deliberative discussions previously convened or co-convened by the Public Policy Center, see PRIORITY LINCOLN FINAL REPORT (2008), *available at* http://ppc.nebraska.edu/program_areas/documents/Mayor%27sDeliberation.htm; BY THE PEOPLE IMMIGRATION REPORT (2007), *available at* <http://ppc.nebraska.edu/ByThePeople/10-07event.htm>; BY THE PEOPLE: A CITIZEN DISCUSSION ON EDUCATION POLICY, *available at* <http://ppc.nebraska.edu/ByThePeople/10-05event.htm>.

techniques can be used – either by the Commission itself or by a group hired by the Commission – whenever the need arises.

6. Describe the project's evaluation plan, including measurement and assessment methods that will verify project outcomes. (10 points)

Evaluation and assessment of project objectives are tied to execution and completion of the project activities. A Final Report will be issued to the project funders and other stakeholders prior to the Nebraska legislative session in January of 2009.

Objective	Measurement and Assessment
<p>Engage a randomly selected group of Nebraskans about e-sharing of health information vis-à-vis a survey(s) and Deliberative Poll.</p>	<ul style="list-style-type: none"> • Lists of randomly selected residents of Nebraska will be used to identify and recruit participants to complete surveys and participate in a Deliberative Poll. • Stakeholders working group composed of members of the NITC, HSPC, the legal team, e-Health council, and others will provide guidance in identifying topics of interest for both the surveys and the Deliberative Poll, and be invited to attend as expert panelists and observers.
<p>Increase knowledge and understanding of the issues surrounding e-sharing of health data, and the key legal and policy questions currently facing state policymakers.</p>	<ul style="list-style-type: none"> • Survey 1 will measure participants' baseline knowledge and attitudes about current legal and policy issues related to e-sharing of health data currently facing the state. • Survey 2 will measure participants' knowledge and attitudes about those same items following the Deliberative Poll. Survey 2 will also measure overall participant satisfaction with the event. • Portions of the Deliberative Poll will be audio-taped to capture qualitative data from the process.
<p>Provide Nebraska's policymakers with meaningful quantitative and qualitative input from a sample of the public about these issues.</p>	<ul style="list-style-type: none"> • The Policy Center will issue a Final Report synthesizing findings from this engagement project to the project funders and other stakeholders, as well as make it publicly available online. The Final Report will be written prior to the beginning of the legislative session in January 2009.

7. Describe the hardware, software, and communications needed for this project and explain why these choices were made. (10 points)

No specialty computer hardware or software, or communications equipment, will be needed for this project.

Financial Analysis and Budget (10 points)

The budget will be scored on reasonableness (up to 5 points) and mathematical accuracy (up to 5 points).

Provide the following financial information:

Category	Description	Request for FY2008-09
1. Personnel Costs		
PI Abdel-Monem	175 hours project mgmt. and survey/delib development	\$8,539
PPC Director Tomkins	19 hours project consultation	\$2,161
Research Specialists	14 hours for survey development and data analysis	\$683
Administrative Assistance	31 hours for logistics and deliberation support	\$1,332
Undergrad Research Assistants	159 hours for briefing docs, delib. support, data entry	\$3,907
	<i>Personnel Subtotal</i>	\$16,623
2. Contractual Services	N/A	\$0
3. Supplies & Materials	paper, envelopes, labels, nametags, signage, etc.	\$366
4. Telecommunications	N/A	\$0
5. Training	N/A	\$0
6. Travel	N/A	\$0
7. Other Costs		
Moderator Stipends	\$100 for MC, \$25 x 3 for group moderators	\$175
Copying/Printing	postcards, surveys, briefing docs, correspondence, etc.	\$1,245
Postage	postcards, surveys, briefing docs, correspondence, etc.	\$893
Facilities	deliberation meeting rooms, A/V equipment, etc.	\$300
Catering	catering \$30/person x 40 people	\$1,200
	<i>Other Costs subtotal</i>	\$3,812
8. Capital Expenditures	N/A	\$0
TOTAL COSTS		\$20,800
General Funds		\$0
Cash Funds		\$0
Federal Funds		\$0
Revolving Funds		\$0
Other Funds		\$0
TOTAL FUNDS		\$0

*Personnel costs are included at the expected hourly rate for the project period, inclusive of salary and benefits. If additional time is needed to complete the project, it will be provided.

Financial Narrative Notes and Instructions

Several categories (see below) **require** further itemization.

1. Please include estimated number of hours or full-time equivalent (FTE) by position. Include separate totals for salary and fringe benefits. If it is necessary to itemize on a separate sheet, include only the subtotal in this table.
2. Please itemize other contractual expenses on separate sheet.
3. Please itemize capital expenditures by categories (hardware, software, network, and other) on a separate sheet.
4. Please itemize other operating expenses on a separate sheet.
5. Please indicate the source of any cash match.
6. Please indicate the source of any in-kind match and how it will be documented.
7. Please provide a breakdown of any other external funding sources. Sources of external funds may include grants from federal agencies or private foundations.

Please keep supporting documentation to a minimum. For example, rather than including a printout of a quotation from Dell for a new computer, include all relevant information in the budget narrative.

Personnel costs are included at the Center's expected hourly rate for the project period, inclusive of salary and benefits. Rates are established using University of Nebraska-Lincoln service center costing guidelines. No new FTE positions are anticipated for this project. If additional time is needed to complete the project, it will be provided and funded by general Public Policy Center operating funds.

Costs are included to conduct a survey of up to 450 people and convene deliberative discussion in Lincoln, Nebraska with approximately 25 participants. We expect up to 80-100 individuals will complete the survey. While the survey will be conducted on-line, it is anticipated that hardcopy surveys will be printed and mailed to 20% of participants, on their request. Supplies and materials for the project, such as paper, envelopes, postcards, mailing labels, name tags, etc. will cost approximately \$366. Printing costs totaling \$1,245 are included for postcards (\$90), hardcopy surveys (\$50), briefing documents (\$1,000), and correspondence/other project copying (\$105). Postage costs of \$893 is budgeted to mail postcards to invite 450 people to participate in the on-line survey; mailing hardcopy surveys and providing pre-paid return postage envelopes; and mailing briefing documents and correspondence to deliberation participants. Costs for hosting a half-day Deliberation also include facilities for meeting room and A/V costs (\$300) and catering to provide a meal for participants (\$1,200).

No hardware or software will be purchased for the project. No on-going operation or replacement costs are anticipated for the project.