

NC Consumer Advisory Council on Health Information Consumer Empowerment Toolkit

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December 21, 2007
Subcontract No. 37-321-0209825

ABOUT NCHICA

NORTH CAROLINA HEALTHCARE INFORMATION AND COMMUNICATIONS ALLIANCE

The North Carolina Healthcare Information and Communications Alliance, Inc. (NCHICA) is a nonprofit consortium of 200 organizations dedicated to improving healthcare by accelerating the adoption of information technology (IT). NCHICA members represent diverse sectors of the healthcare community, including providers, payers, vendors, professional societies and law firms. To see a list of members, [click here](#).

NCHICA's role is to act as a neutral forum to bring together the many sectors of the healthcare industry. Members address how best to accelerate the adoption of IT in healthcare by considering clinical needs, policy questions and technology issues.

ABOUT NC HISPC

NORTH CAROLINA HEALTH INFORMATION SECURITY AND PRIVACY COLLABORATION

In October 2005, the Office of the National Coordinator for Health Information Technology and the Agency for Healthcare Research and Quality awarded the Privacy and Security Solutions for Interoperable Health Information Exchange contract to RTI International. RTI, in collaboration with the National Governors Association Center for Best Practices, formed the Health Information Security and Privacy Collaboration (HISPC) and invited states and territories to submit proposals to participate in the project. HISPC was designed to examine privacy and security laws and business practices that affect the ability of states and territories to exchange electronic health information within themselves and among each other.

NCHICA submitted a proposal, and in April 2006, was awarded the contract to represent North Carolina. Since the project's commencement, teams of healthcare stakeholders have worked collaboratively to identify, assess and develop plans to address variations in organization-level business policies and state laws that affect privacy and security practices that may pose challenges to health information exchange (HIE).

Acknowledgements

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EXECUTIVE SUMMARY

Historical Background

In April 2004, President George W. Bush articulated his vision for the future of healthcare in the United States through an Executive Order that authorized Secretary of the Department of Health and Human Services (HHS) Michael Leavitt to establish the Office of the National Coordinator for Health Information Technology (ONC). ONC provides leadership for the development and nationwide implementation of an interoperable health IT infrastructure to improve the quality and efficiency of healthcare and consumers' ability to manage their care and safety. The National Coordinator for Health Information Technology is the chief advisor to the Secretary of HHS on the actions needed to meet the president's call for widespread adoption of secure, interoperable health IT.

In October 2005, ONC and the Agency for Healthcare Research and Quality awarded the Privacy and Security Solutions for Interoperable Health Information Exchange contract to RTI International. RTI, in collaboration with the National Governors Association Center for Best Practices, formed the Health Information Security and Privacy Collaboration (HISPC) and invited states and territories to submit proposals to participate in the project. HISPC was designed to examine privacy and security laws and business practices that affect the ability of states and territories to exchange electronic health information within themselves and among each other.

NCHICA submitted a proposal, and in April 2006, was awarded the contract to represent North Carolina. Since the project's commencement, teams of healthcare stakeholders have worked collaboratively to identify, assess and develop plans to address variations in organization-level business policies and state laws that affect privacy and security practices that may pose challenges to HIE.

During the assessment phase of the HISPC project, obtaining consumer input was cited as the most difficult challenge the project leaders faced. Consumers said they were unable to participate due to lack of transportation, lack of trust with a government-sponsored project and the inability to attend meetings during the traditional workday. These issues continue to pose a challenge for those interested in directly engaging consumers in discussions, workshops and projects related to health IT and exchange.

In August 2006, NCHICA responded to this challenge by forming the North Carolina Consumer Advisory Council on Health Information (NC CACHI). Although in its infancy, NC CACHI continues to gain the interest of consumers and respect of technology professionals.

Why Consumer Empowerment Matters Now

The capability to share health information electronically has transformed the healthcare community. The NC HISPC project was designed to examine privacy and security laws and business practices that affect the ability of states to exchange electronic health information. This is important as a foundation to enable consumer empowerment in HIE. Consumers have not traditionally been involved in healthcare stakeholders' discussions about developing policy, technology and law to exchange health information electronically.

The purpose of this project is to examine HIE issues and how they affect patient/consumer empowerment. A lack of standards in privacy policies and technology operability prevents providers from communicating consent policies clearly to patients, resulting in distrust from disparate standards and policies. Patients have not been involved in discussions of how to implement HIE and are not aware of the ways health information can be shared.

NCHICA is committed to empowering consumers by implementing awareness programs and providing tools to individuals and organizations that are interested in consumer health information issues.

Due to recent technological advances, information can be shared among many types of healthcare professionals. With the federal government funding the Nationwide Health Information Network, which creates the infrastructure for sharing patient information across organizations such as labs, pharmacies, hospitals, clinics, physician practices and state agencies, the awareness of patient empowerment is emerging.

Sharing medical information extends beyond just doctor's offices involved in patient care or health insurance companies that pay the claims. Secondary users of healthcare data include researchers, marketing departments, employers and financial organizations administering health savings accounts.

There are also health record banks that allow patients to decide who has access to their medical records, which are stored in a secure repository similar to a financial bank. These "information banks," however, may be interested in the ability to collect and sell patient information to external parties for research or marketing purposes.

Ultimately, patients' trust in the security and privacy of their medical data will affect how they share their information. At present, what is not clear is patients' awareness of the "trade-offs between legitimate concerns about their privacy and the benefits of making more complete information available to the providers" so that physicians can provide optimal care based on more comprehensive information. The patient is the person with the most at stake and is in the best position to provide information. Empowering a patient with the knowledge and ability to determine how his or her medical information is shared will be critical in the emerging technological environment.

Consumer Empowerment in North Carolina

Stakeholders involved in the NC HISPC project want to ensure:

- Health IT solutions support the right of consumers to control access to their private health information
- Consumers are given ample opportunity to understand the impact of health IT on their healthcare decisions and/or actively participate in the planning, design and implementation of health information networks, personal health records (PHRs) or other health IT projects designed to exchange their health information

NC HISPC found that due to the misinterpretation and conflicts of laws and lack of electronic data security standards, providers sometimes engaged in inappropriate behaviors regarding privacy and security policies and the sharing of health information with patients and other providers. Examples of these behaviors include withholding information from patients and having consent policies designed primarily to reduce the clinician's liability risks rather than support the consumer's right to privacy.

Without understanding and empowerment in HIE, consumers are not likely to trust electronic health records (EHRs) or participate in the use of PHRs, ultimately enabling consumers to control their medical records. Physicians inherently rely on consumers to embrace the technology and associated privacy policies so that appropriate exchange of health information can take place.

Enabling Consumer Empowerment

North Carolina healthcare thought leaders support improving the quality of healthcare for individuals seeking treatment in the state through consumer empowerment. This will ultimately ensure that relevant health information is exchanged in a routine, timely and secure manner to improve health and wellness.

NCHICA's commitment to enabling consumer empowerment will be realized through the following goals:

- Encourage collaboration between consumers, providers and policymakers on policy standards and clarifications
- Implement public and private awareness programs for consumers, providers and vendors to ensure policies are communicated clearly
- Establish a project examining adoption and use of person-oriented HIE, such as PHRs
- Develop programs aimed at raising awareness of the risks, benefits and impact of health IT among a cross-section of consumers
- Build consumer empowerment champions and sponsors so funding and opportunities are provided for consumer engagement in HIE discussions and decision making
- Actively engage consumers on the impact of health IT

NC CACHI will advise NCHICA's emerging North Carolina Health Information Exchange Council (NC HIE Council) on consumer issues so it can, in turn, advise public policymakers and participate in demonstration projects. The NC HIE Council strives to build leadership and health IT supporters among public

policymakers, the healthcare community and consumers by developing and implementing a policy, legal and technological framework to adopt health IT that enables HIE. As individuals become aware of the benefits of exchanging health information in an electronic and secure method, NC HIE Council will seek support from their supporting organizations as well as public policymakers at the local and state level to participate in and fund collaborative HIE demonstration projects.

The primary goal of the NC HIE Council is to design and implement an infrastructure for the routine, timely and secure exchange of health information, relying on informed authorization and consent by the individual or person responsible for that individual's care, no matter where the health information may reside. The model needs to be supported by carefully defined policies for authentication, authorization, protecting data in transit and at rest, and responsibilities of the individual for the care of his or her records. Many healthcare consumers are unaware of the implications of access to personal health information and the consequences of unauthorized access and misuse of that information.

A foundation for this framework is the Markle Patient and Consumer Principles to guide the protection of medical information exchanged electronically between healthcare institutions. These include:

1. Individuals should be able to access their health and medical data conveniently and affordably.
2. Individuals should be able to decide (i.e. authorize) when their health data is shared and with whom. Individuals should be able to refuse to make their health data available for sharing (i.e. opt-out).
3. Individuals should be able to designate someone else, such as a loved one, to have access to and exercise control over how their records are shared.
4. Individuals should receive easily understood information about all the ways in which their health data may be used or shared.
5. Individuals should be able to review which entities have accessed their personal health data.
6. Electronic health data exchanges must protect the integrity, security, privacy and confidentiality of an individual's information.
7. Independent bodies, accountable to the public, should oversee the electronic health data exchanges. No single stakeholder group should dominate these oversight bodies. Consumer representatives selected by their peers should participate as full voting members.

**North Carolina Health Information Security and Privacy Collaboration
Consumer Empowerment Toolkit**

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PUBLIC COMMENTS

Your comments and recommendations are important to us. Please send your feedback to asantiago@tmfloyd.com.

Instructions:

1. Identify which section of this document you are reviewing (A-C)
2. Open the document in the "read only" mode
3. Identify the line number you are commenting on
4. Insert your suggestions into the table below

North Carolina Health Information Privacy and Security Collaboration (NC HISPC) Document Review			
Choose One			
A. __ NC HISPC Consumer Empowerment Toolkit Executive Summary			
B. __ NC HISPC Consumer Empowerment Toolkit			
C. __ NC HISPC Consumer Empowerment Awareness			
Line #	Text you are commenting on	Issues	Recommendations
Optional			
Name:			
Organization name, if applicable:			
Title:			
Phone:			
E-mail:			
<input type="checkbox"/> Yes, keep me informed of future releases.			

PURPOSE OF THE CONSUMER EMPOWERMENT TOOLKIT

The purpose of the Consumer Empowerment Toolkit is to provide avenues to engage and involve the consumer in discussions about healthcare information exchange (HIE) and technology (HIT) so that they can make informed decisions about sharing their health information.

HOW TO USE THE CONSUMER EMPOWERMENT TOOLKIT

This toolkit contains three components:

1. The **Executive Summary** describes how this project was formed and funded, its objectives, and its impact to consumers.
2. The **Consumer Empowerment Toolkit** includes resources and foundational documents to assist interested consumers in forming health information related consumer advisory committees or councils.
3. The **Consumer Empowerment Awareness Messages Toolkit** contains a set of messages and presentations that raise public awareness about the Health Information Security and Privacy Collaboration, the North Carolina Healthcare Information and Communications Alliance and the North Carolina Consumer Advisory Council on Health Information.

This toolkit will be regularly updated, maintained and publicly available on the NCHICA Web site at <http://www.nchica.org>.

CHARTER

Purpose of the Council Charter

Charters such as the example contributed by NC CACHI authorize the organizer to form a committee or start a project team. It should include the purpose of the committee or project, mission, goals, organizational structure, identified leaders, members and their roles, and meeting frequency.

Charters describing your group's objectives and organizational structure are usually required by governmental agencies, associations or potential funding sources.

The NC CACHI Charter

Note: example only, do not edit this section

PURPOSE: The purpose of the North Carolina Consumer Advisory Council on Health Information (NC CACHI) is to engage patients (healthcare consumers) in providing input and feedback on topics related to health information.

NC CACHI is a unique healthcare consumer group formed for grassroots input and participation to explore ideas and issues surrounding health information, such as privacy and EHRs. NC CACHI provides an opportunity to influence both state and national policy with regard to healthcare consumers' ideas and concerns about health information and technology, and will participate in trying to find a balance between a patient's need for privacy and the healthcare system's need for access to personal health information.

MEMBERSHIP: In order to achieve a diverse representation of North Carolina healthcare consumers, it is essential that individuals chosen to be members of NC CACHI have varied backgrounds including gender, age, race, education, geography, health status, recent experience with the healthcare system, etc. The 15-member panel will have rotating membership, with five members serving one-year terms, five serving two-year terms and five serving three-year terms. NC CACHI will be supported and assisted by a group of experts who will serve on a Resource Panel.

RESPONSIBILITIES: NC CACHI members will be expected to attend monthly meetings. They should participate in NC CACHI activities in order to raise awareness on the impact of health IT to the consumer.

ACTIVITIES: Activities include participation in consumer focus groups and research studies to find ways to educate and empower North Carolina healthcare consumers.

MEETINGS: NC CACHI members will meet the third Thursday of each month from 2:30 - 4:30 pm at the NCHICA office. There may be opportunities for optional special topic meetings outside of the regular meetings.

RECRUITING STRATEGY

As you think about forming a consumer-related organization, there are three models to consider. You will need to decide whether your consumer group should consist of

professional advocates from governmental agencies or nonprofit associations or individuals interested in health IT topics.

Because governmental agencies and professional advocates or associations represent a group of consumers, they may have more resources to assist or collaborate with your organization. Professional resources may require less education and be able to translate the context of the issues in their particular areas of interest. They may also be able to contribute expert knowledge from their perspective. These governmental agencies or professional groups will need to know precisely what the objectives of your group are and your plan to meet those goals so that they may determine how they fit or conflict with their organizations' goals.

Considering a grassroots model that consists of individuals with health IT interests may pique the interest of professionals and potential funding sponsors, but it is not without its challenges. During the assessment phase of the Health Information Security Privacy Collaboration, obtaining consumer input was cited as the most difficult challenge to the states involved in the project. Consumers cited that they were unable to participate due to lack of transportation, lack of trust with a government-sponsored project and the inability to attend meetings during the traditional workday. These issues continue to pose a challenge for those interested in the grassroots model.

Another model under consideration by those forming healthcare consumer groups is a combination of the two, or the hybrid model. In the hybrid model, the consumer group would consist of governmental agencies, professional associations or advocates, and individuals. The hybrid model of consumer-related groups is currently utilized by most associations and advocacy groups. It allows members the option to participate and have access to subject experts and resources while maintaining their individual views.

How to Recruit

Once you have determined your group's goals and objectives and what kind of participants you desire, it is time to find sponsors that will assist with meeting space, funding, public relations, administrative support or access to their members.

This toolkit also includes a set of messages and presentations to assist you in raising public awareness about the formation of your healthcare consumer council, objectives, meetings and membership.

Where to Recruit

There are many ways and places to find people and professionals who may be interested in participating or supporting your efforts. Your recruiting strategy will depend on the membership model you choose to adopt.

If you are approaching a professional association or advocate, you may wish to send them an article or newsletter, attend one of their meetings, or invite them to your meeting. Consider sending the invited organization your meeting's agenda, organizational charter and a letter of support by a credible organization.

Internet sites like MoveOn.org and Meetup.com simplify posting information about your organization and meeting times. There is also the capability to network with similar organizations and link to their sites as well. Trade shows or public gatherings that allow nonprofits to exhibit will give you an opportunity to promote your organization in a neutral setting. Other potential places to recruit participants or sponsors include homeowner or community organizations, employers, community colleges, and universities.

NC CACHI compiled the following list of organizations that may be interested in learning about its efforts.

Potential NC Healthcare Consumer Members or Resource Panel Experts

<http://www.dhhs.state.nc.us/aging/trade.htm#115>

<http://www.wral.com/news/9351814/detail.html>

<http://www.ncchild.org/>

<http://www.uncg.edu/hhp/cwhw/>

<http://womenscenter.unc.edu/>

<http://www.lwvnc.org/volunteer.html>

<http://www.doa.state.nc.us/hub/>

<http://www.dhhs.state.nc.us/pressrel/8-12-05.htm>

http://www.healthcharities.org/org_profile_chc2729/org_profile_chc_show.htm?at_trib_id=2871

<http://www.ncchca.org/>

<http://152.3.224.76/campaign/news/reynolds.html>

<http://www.acluofnorthcarolina.org/>

<http://www.mha-nc.org/>

<http://www.fpg.unc.edu/~ncodh/WomensHealth/index.htm>

<http://www.ncjustice.org/>

<http://www.ncminorityhealth.org/omhhd/index.html>

<http://www.healthwellnc.com/hwtfc/htmlfiles/news2005.htm>

http://www.governorsinstitute.org/index.php?option=com_content&task=view&id=49&Itemid=91

<http://www.unca.edu/news/releases/2006/MLKDay.html>

MEMBERSHIP CRITERIA

Criteria for membership will depend on the purpose and context in which the consumer group exists. Membership should represent the consumers in such a way that the mission of the organization can be accomplished. For NCHICA, it felt that a variety of consumers from diverse backgrounds would be appropriate for its formation. With no consumers to begin NC CACHI, NCHICA assembled a panel of HIE and technology experts to assist in the Council's formation. The NC CACHI Resource Panel developed invitations, surveys and membership applications to help recruit potential members.

When starting a group with a specific niche such as health information exchange and technology, it is difficult to determine what the appropriate membership criterion is. Although NC CACHI is a workgroup within NCHICA, they chose to extend participation in this new consumer empowerment the Alliance's membership.

Current membership within NC CACHI primarily consists of individuals with IT or healthcare-related backgrounds who have received formal higher education. Due to their professional and educational backgrounds, these consumers have been able to discuss issues from a consumer point of view while also understanding the technical and policy issues in HIE.

The consumers who come from administrative or academic backgrounds have been able to accommodate the monthly NC CACHI meeting, whereas those who work in middle management, skills or trades, or are unemployed are more difficult to engage in meetings requiring them to be absent from work. However, they may still be interested in occasional participation. These consumers could be engaged through focus groups, workshops or surveys, with an open invitation to attend a meeting as their schedule permits. In this way, awareness and outreach activities such as the focus groups or workshops can be a recruiting tool for the consumer group.

Although membership diversity is not without its challenges, North Carolina healthcare stakeholders are committed to finding creative ways to reach out to all types of healthcare consumers. Please contact Holt Anderson, Executive Director of NCHICA, at holt@nchica.org with your suggestions.

Roles and Responsibilities

At the beginning, there are no members to assign roles or responsibilities. The foundational work will be performed by a committed individual or small group lending their skills, expertise, technology and affiliations to jump-start the consumer group.

In the case of NC CACHI, its sponsor (NCHICA) felt that a 15-member council and a separate expert resource panel would best serve the needs of NC CACHI's mission. NC CACHI consists of purely healthcare consumers.

The NC CACHI Resource Panel consists of health IT professionals who specialize in specific areas such as EHRs, nursing informatics, privacy and security. They support and assist the Council members by identifying educational and presentation opportunities, clarifying questions on issues, facilitating meetings, funding, recruiting, and performing administrative functions.

Currently, two members of the Resource Panel serve as co-chairs to aid NC CACHI members as they formalize their operations. The co-chairs act as liaisons between the Council members and the Resource Panel. Once the Council members have determined they are ready to select their own chair and other representatives, the Resource Panel will begin transitioning operations to the Council. Until NC CACHI is formally set up and operational, it may be helpful to have at least one Resource Panel member (or an external agent) to assist the Council through the formation process.

An advantage of the Resource Panel assisting with meeting logistics, facilitation and minutes is that it frees up the Council members to focus on their discussions rather than being concerned with generating minutes, agendas, or other documentation or deliverables. The co-chairs and other Resource Panel members can assist with these activities until the Council determines how it wants to handle these issues.

Role	Responsibility	Main Tasks
Host <i>*May not necessarily be a member of the consumer group</i>	Provide meeting place and refreshments	<ul style="list-style-type: none"> ▪ Obtain RSVPs from recorder ▪ Order refreshments ▪ Prepare refreshments ▪ Conduct welcome message to meeting attendees
Facilitator	Foster an objective and open environment for discussions	<ul style="list-style-type: none"> ▪ Extend meeting invitations ▪ Arrange for speakers/presentations ▪ Develop meeting agenda ▪ Ensure meeting documents are distributed prior to meeting ▪ Keep discussions to agenda items ▪ Maintain meeting scope and time allowance ▪ Send thank you notes to speakers
Recorder	Develop and maintain meeting documentation	<ul style="list-style-type: none"> ▪ Assist facilitator with meeting preparation, distribution of meeting documentation such as agenda, presentations or minutes ▪ Distribute meeting announcements and materials ▪ Maintain RSVPs ▪ Take meeting minutes ▪ Obtain a copy of the sign-in sheet from membership representative

Role	Responsibility	Main Tasks
Recruitment	Develop and implement strategies to recruit potential members	<ul style="list-style-type: none"> ▪ Identify outreach opportunities ▪ Work with public relations firm to raise awareness of the Council's existence and purpose
Membership	Develop, implement and maintain membership tools that ensure the group has updated membership information	<ul style="list-style-type: none"> ▪ Maintain sign-in sheets and contact lists ▪ Maintain confidentiality agreements
Fundraising	Develop and implement fundraising strategies to ensure the group's sustainability	<ul style="list-style-type: none"> ▪ Identify potential sponsors and funding opportunities ▪ Assist with grant and proposal writing
Public Relations	Develop and execute strategies to raise public awareness of the group's existence and events	<ul style="list-style-type: none"> ▪ Ensure all meeting and events are publicized ▪ Ensure Web site is maintained ▪ Build relationships with other consumer related organizations or programs
Resource Panel Member <i>*Is not a member of the consumer group</i>		<ul style="list-style-type: none"> ▪ Assist with grant and proposal writing ▪ Assist with development and implementation of the group ▪ Assist with development of strategies, awareness and education workshops
All Members		<ul style="list-style-type: none"> ▪ Suggest speaker opportunities ▪ Suggest potential projects ▪ Notify fundraiser of potential funding opportunities

Subject Matter Experts

As an educational opportunity and to encourage dialogue between consumer group members, subject matter experts are often invited to speak about topics of interest to the members. Resource Panel members are also considered to be subject matter experts and a potential source for speakers as well. The following have been identified or are suggested as potential subject matter experts or Resource Panel members.

- Women's healthcare
- Senior citizens organization
- Mental health organization
- ACLU
- HIV and other stigmatizing conditions
- Health departments
- Community clinics
- Patient privacy issues (Markle, Patient Privacy Rights, Health Privacy Project)
- Underprivileged or underserved populations
- State and federally funded health IT projects
- Healthcare technology software vendors
- Legal profession or State Attorney General's Office
- Policymakers such as legislators
- Healthcare organization workgroups or conferences
- Media

Invitation to Join

The following invitation was contributed by NC CACHI.

Greetings,

The NC Health Information Security Privacy Collaboration is seeking 15 volunteers to serve on a Consumer Advisory Council that will assist with exploration of ideas and issues related to health information technology, such as privacy and EHRs. The Council will be supported and assisted by a group of volunteer subject matter experts who will serve as a Resource Panel.

The Council will be selected from those who complete the online nomination form. NCHICA will review those who are nominated and select the final 15 members. Council members will be chosen to represent individuals across various criteria including gender, age, race, education, geography, health status, recent experience with the healthcare system, etc. Council members will be asked to represent individuals in their state (and not a particular organization). Plans are for appointing a 15-member panel with five serving one-year terms, five serving two-year terms and five serving three-year terms. Once appointed, the group will identify their “rules of engagement” within the Council and develop plans for meeting locations and agendas.

Plans are for the Council to meet on a monthly basis with each meeting providing a presentation on a topic of interest. There will also be time to discuss relevant issues where the Council will help NCHICA understand the consumer’s perspective. The Council will normally meet from 11:00 am – 3:00 pm on the third Thursday of each month, with lunch provided. The first meeting will be held on **August 28** (11:00 am – 3:00 pm, NCHICA office in Research Triangle Park, NC).

Some of the topics that are being considered for presentation to the Council include those bulleted below. The Council may also identify additional topics of interest to them.

- What does it mean to be an informed healthcare consumer in this age of technology?
- The effects of opting in or out of a health data exchange
- The latest NC consumer opinion profile from recent privacy and security research surveys
- How information regarding stigmatizing conditions (such as HIV or alcoholism) is handled, used and disclosed

If you know of someone you would like to nominate or who might volunteer, please ask them to complete the online nomination form. The first 100 responders will be considered for Council membership. The nomination form can be completed at <http://www.surveymonkey.com/s.asp?u=907342384346> and should be submitted no later than **Aug 6**. People who are nominated but are not selected for the 15-member group may still participate as a volunteer for the resource group to the Council.

Questions or comments may be sent to me at the e-mail address below. Thank you for your consideration and assistance in this important project.

W. Holt Anderson, Executive Director

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Invitations and Nominations

The nomination form for NC CACHI was performed using the Web-based Survey Monkey (we realize this limits those responding to the invitation to those with access to computers—we are seeking other methods such as focus groups to reach out to other consumers).

The Survey Monkey questions that were asked (and options given) are as follows:

1. Name
2. Address
3. Phone
4. E-mail
5. Where do you live?
 - a. Eastern North Carolina
 - b. Central North Carolina
 - c. Western North Carolina
6. Your age?
 - a. 20 or younger
 - b. 21-30
 - c. 31-40
 - d. 41-50
 - e. 51-60
 - f. 61-70
 - g. 71-80
 - h. 81-90
 - i. Over 90
7. Your education?
 - a. Less than high school
 - b. High school
 - c. Trade school
 - d. Associate degree
 - e. Bachelor's degree
 - f. Master's degree
 - g. Doctoral degree
 - h. Other (please specify)
8. Household status?
 - a. Single, live alone

- b. Single, live with others
 - c. Married, live with spouse
 - d. Married, live with spouse and children
 - e. Other (please specify)
9. Please rate your thoughts for each item (strongly disagree to strongly agree options):
- a. Information technology is a good investment for healthcare.
 - b. Information technology can help improve patient care.
 - c. Information technology can help protect patient privacy.
 - d. I will commit to meeting monthly (3rd Thursday 11 am - 3 pm) if appointed.
 - e. I will work on issues with/for the group between meetings.
 - f. I will work on documents the group decides to produce.
 - g. I would like to serve for 1 year.
 - h. I would like to serve for 2 years.
 - i. I would like to serve for 3 years.
10. Please rate the following (never, once in a while, most of the time, always, N/A):
- a. I use the Internet to obtain health information.
 - b. I trust health information on the Internet.
 - c. I trust my physician in protecting my health information.
 - d. I trust others in the health system to protect my health information.
 - e. I trust my insurance company in protecting my health information.
11. What would best describe your encounters with the healthcare system in the past year (no encounters, 1-2 encounters, 3-5 encounters, 6-10 encounters, 11 or more encounters)? This could be a doctor's office, clinic, hospital, etc. (assume you accompanied this person if you were not the patient).
- a. You
 - b. Spouse
 - c. Children
 - d. Other family members
 - e. Friend
12. In general, what would best describe your encounters with the healthcare system (for yourself or with others)?
- a. Miserable
 - b. Not so good
 - c. Unsure
 - d. Pretty good
 - e. Excellent
 - f. Other (please specify)
13. Is there some portion of the public that you think you would be especially able to represent well?
14. Please briefly describe why you would like to be considered as a representative of NC CACHI.

HOSTING MEETINGS

As the facilitator or host, you serve a vital role by fostering an objective and open environment for the attendees to learn and discuss how healthcare professionals use personal information for treatment, insurance claims payment, operations, marketing, research, public health and other uses.

When serving as the host or facilitator, consider excusing yourself from actively participating in the discussions. By acting as a neutral facilitator, you ensure the meeting's objectives are met, accurate notes are taken by the recorder, discussions stay within the subject matter boundaries, and most importantly, that the attendees have been given ample opportunity to respond to the presentation or issue at hand.

Here are a few tips to help the attendees feel comfortable:

- As the attendees vocalize their views, recommendations or concerns, acknowledge and thank them for sharing their thoughts.
- Steer them away from debating or consulting each other.
- If a scheduled speaker or Resource Panel attendee uses technical or legal terms, ask them to briefly define or clarify the term and consumer context.

Meeting Outline – Host / Facilitator

1. Welcome the attendees to your meeting.
2. Introduce yourself. Include your role in the organization and why you are interested in healthcare consumer issues.
3. Allow each attendee to introduce themselves.
4. Ask them to include their particular healthcare consumer issue in their introduction.
5. Logistics:
 - a. Have attendees sign-in.
 - b. Verify that their confidentiality agreements have been signed.
 - c. Determine whether refreshments will be provided. If so, have them ready to serve about 15 minutes prior to meeting start.
 - d. Let attendees know where they may find restrooms.
6. Review the meeting's agenda and objectives.
7. Verify that the attendees have all documents for today's meeting.
8. Read the confidentiality statement:
 - a. During our meeting today, we will have someone take notes to ensure that topics you are interested in exploring are followed up on by the. However, we do not want you to feel free to say what is on your mind. Therefore, if there is any personal information you do not wish to be included in the notes, just let us know, and we will honor that request.
9. Address all of the items on the agenda.
10. Provide closing remarks.

Meeting Agenda	
Date	
Time	2:30 pm - 4:30 pm Coffee and snacks provided RSVP to cathyconsumer@isp.com
Host	
Facilitator	
Recorder	
Web Meeting Information	Please e-mail the host or facilitator to receive remote access instructions for this meeting.
Who Should Attend?	
Meeting's Theme	

Agenda ID	Agenda ID and Items
2:30 pm	<ol style="list-style-type: none"> 1. Introductions 2. Approval of previous minutes
2:40 pm	<ol style="list-style-type: none"> 3. Previous subjects <ol style="list-style-type: none"> a. Federal health information initiatives b. Feedback on presentation from last meeting
3:10 pm	<ol style="list-style-type: none"> 4. Consumer council business - council members <ol style="list-style-type: none"> a. Sustainability b. Vision for the council c. Leadership of council d. Procedures, etc. e. Membership recruiting 5. Topics or speakers of interest for future meetings
4:10 pm	<ol style="list-style-type: none"> 6. New projects to consider
4:20 pm	<ol style="list-style-type: none"> 7. Next meeting <ol style="list-style-type: none"> a. Confirm date b. Confirm agenda items
4:30 pm	<ol style="list-style-type: none"> 8. Adjourn

Meeting Minutes		
Date		
Time		
Host		
Facilitator		
Recorder		
Web Meeting Information		
Meeting's Theme	This meeting's agenda is attached. It will focus on the council's sustainability.	
Member Attendees	Name, Organization Name, Organization Name, Organization	
Resource Attendees	Name, Organization Name, Organization Name, Organization	
Visitors	Name, Organization	
Meeting Notes / Action Items	Task Owner	Status Due Date Completed Late
Brief description of discussion items.		
Action items: Bold action items and include a due date for follow-up.	Each action item should be assigned to a task owner. The task owner may either complete the task or delegate this task to another. However, ultimate responsibility of the task's completion is on the task owner. Usually these tasks will be completed outside of the realm of the meetings. The task owner should report their status	Including a due date for the task is critical. Because the council only meets once a month, these tasks can roll from meeting to meeting and never see completion.

	to the co-chairs about twice per month.	
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Upcoming Meetings		
Date	Location / Format	Agenda

OPERATIONAL TOOLS

Regardless of what membership model you choose to adopt, potential sponsors and members will expect you to document and maintain accurate records of your events, meetings and expenditures.

The following examples of operational tools are designed to help you consider what types of activities you may engage in and their potential funding needs.

Future updates of this toolkit will include executive director job descriptions, proposal templates, letters of support, timesheets and billing invoice templates. If you wish to contribute to this developing toolkit, please refer to the acknowledgements page for contact information.

Budget Template

Annual Budget Draft

Expenses

		Estimated	Actual
Total Expenses		\$180,700.00	\$0.00

	Estimated	Actual
Program Development		
Consumer Awareness	\$30,000.00	
Projects	\$20,000.00	
Privacy Issues	\$15,000.00	
Focus Groups (2 @ 2500)	\$5,000.00	
Totals	\$70,000.00	\$0.00

	Estimated	Actual
Office & Utilities		
Office Space	\$3,000.00	
Utilities	\$1,200.00	
Phone	\$3,000.00	
Totals	\$7,200.00	\$0.00

	Estimated	Actual
Travel Reimbursement		
Lodging	\$10,000.00	
Mileage	\$7,000.00	
Food	\$7,000.00	
Totals	\$24,000.00	\$0.00

	Estimated	Actual
Technology		
Copier	\$2,000.00	
Webex	\$2,000.00	
Computer Equipment	\$3,000.00	
Web Site	\$5,000.00	
Totals	\$12,000.00	\$0.00

	Estimated	Actual
Membership Development		
Speaker Stipends	\$10,000.00	
Publicity	\$10,000.00	
Totals	\$20,000.00	\$0.00

	Estimated	Actual
Labor		
PT Director (Optional)	\$25,000.00	
Administration Staff	\$10,000.00	
Totals	\$35,000.00	\$0.00

	Estimated	Actual
General Administration		
Postage / Office Supplies	\$7,000.00	
Printing Fax Services	\$5,500.00	
Totals	\$12,500.00	\$0.00

Confidentiality Agreement

First, middle, last name:	
Title / position:	
Organization name:	
Address:	
City, state, zip code:	
E-mail address:	
Office phone:	
Cell phone:	

CONFIDENTIALITY STATEMENT

As a guest, Council member or expert resource, I will not at any time disclose or use, either during or subsequent to my attendance at meetings or participation in the Council, any information, knowledge or data that I receive or develop during my attendance at meetings or participation in Council-supported events or projects that is considered proprietary by the Council or confidential by a fellow Council member, without their direct permission. Such information, knowledge or data may include, but is not limited to: discussions, print screens, presentations, contact lists, diagrams, draft or final documents, and accounting or financial data.

I further agree that upon termination of my tenure with the Council, I shall promptly return or destroy any and all documents containing the above information, knowledge or data, or relating thereto, to the Council.

Name (please print) Date

Signature

Please send or fax this form to:
 Attn:
 Fax:

Expense Report Template

Insert Logo Here

For Office Use Only

PURPOSE: _____

Invoice Number: _____

PAY PERIOD: From _____

Account Number: _____

To _____

Reimbursement check payable to:

Name _____

Email _____

Address _____

Phone _____

Date	Activity / Description	Mileage Distance	Mieage Total	Hotel	Travel	Meals	Cab Fares	Parking	Phone / Internet
			0.00						
			0.00						
			0.00						
			0.00						
		0	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -

Subtotal

Advances Received

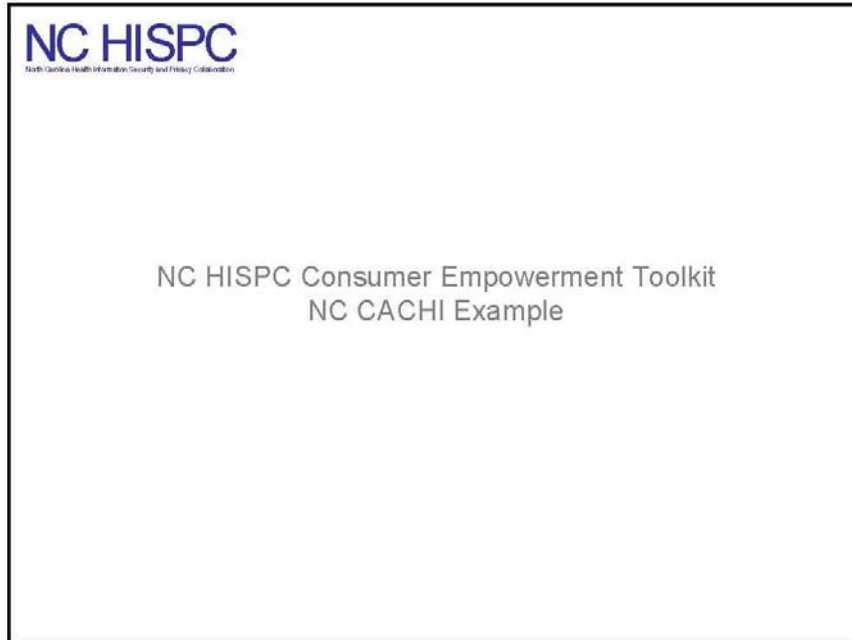
Reimbursement Total

APPROVED: _____

NOTES:

COMMUNICATION TOOLS

Public Messages and Campaign

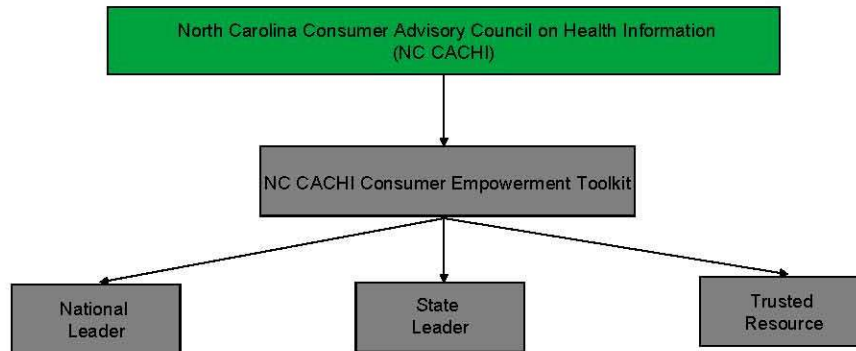


1. Distillation and Core Messaging

NC CACHI Audiences

- Health IT community
- Other state and community consumer groups
 - Patient Privacy Rights
 - www.patientprivacyrights.org
 - Health Privacy Project/Consumer Coalition for Health Privacy
 - www.healthprivacy.org
 - AHIC Workgroup on Consumer Empowerment
 - www.hhs.gov/healthit/ahic/consumer/
- North Carolina educated consumers
 - Membership
 - Understanding

NC CACHI Brand Message Framework



NC CACHI Consumer Empowerment Toolkit Messaging

Message

- NC CACHI provides information for the education and motivation of individuals in relation to managing their patient information
- The free NC CACHI Consumer Empowerment Toolkit provides a trusted framework for consumers and organizations to understand the rewards and risks associated with forming consumer workgroups of their own.

Proof Points

- National and state
 - Hosted consumer awareness meetings with Markle Foundation, Patient Privacy Rights and Dossia
 - HISPC NC CACHI report
 - NHIN 2 trial implementations
 - Viewed as a role model nationally by other consumer groups such as Patient Privacy Rights, Health Privacy Project and AHIC Workgroup on Consumer Empowerment
- Trusted resource
 - Formed as an independent consumer forum
 - Expert panel resources include
 - Nursing Informatics Program Director, Duke University School of Nursing
 - PhD candidate, UNC Greensboro
 - Information security consultants
 - Electronic health records vendors
 - Privacy advocates
 - Started by NCHICA and supported by NC HISPC

2. Public Relations Campaign

Public Relations Campaign

- Objectives and Target Audiences
 - Heighten organizational awareness of the NC CACHI Consumer Empowerment Toolkit
 - To national health IT trade media as well as general healthcare and North Carolina consumer publications to increase awareness among health IT stakeholders and educated healthcare consumers
 - To state and local publications to increase consumer awareness
- Public Relations Audience Segmentation
 - North Carolina government affiliates
 - Media
 - National health IT reporters
 - National general healthcare reporters
 - Statewide consumer reporters (including public service announcements)

Public Relations Campaign Process

- NC CACHI Copyediting
 - Zarb to review and edit toolkit
- NC CACHI News Release
 - Identify NC CACHI spokespeople
 - Develop and distribute NC CACHI Consumer Empowerment Toolkit news release based on toolkit launch
 - Conduct telephone outreach following news release distribution
 - Schedule media interviews per interest and NC CACHI spokespeople
- Public Service Announcements - TBD 2008 and executed by NC CACHI
 - Write, coordinate and submit public service announcements
 - Distribute public service announcements via national public radio
 - WUNC, www.wunc.org
 - WSHA, www.wshafm.org
 - WCPE, www.theclassicalstation.org
 - WNCU, www.wncu.org

E-mails to Members

It should be determined when and for what reasons the members of the consumer group should be contacted through e-mail. One critical issue to discuss is whether members can be e-mailed by external sources such as vendors, marketers or other interested parties such as the media or researchers.

All communications should include the logo of the group or its sponsoring organization and a consistent font and format. Other items that may be included are the Web site address and any contact information (e-mail, physical addresses, etc).

Meeting Reminder 1

This is a reminder of the meeting on Thursday for the Healthcare Consumer Empowerment Council from 2:30 - 4:30 pm in the conference room. Attached are the minutes for the last meeting and the new agenda.

We look forward to seeing you! Please RSVP if you are able to attend. Lunch will be served.

Mark your calendar for the next meeting on _____ in the conference room from 2:30 - 4:30 pm

Thanks,
Cathy Consumer

Meeting Reminder 2

**You are invited to attend
Healthcare Consumer Empowerment Council Meeting
September 13, 2007
11:30 am - 1:00 pm
Conference Room
Lunch will be provided
RSVP to cathyconsumer@isp.com
Directions to the meeting can be found at <http://www.xxxxxxxx.com>**

REMOTE ACCESS:

CONNECT TO THE WEB CONFERENCE:

1. Click on the following link or paste it into your Web browser:
<https://www.gotomeeting.com/join/XXXXXXXXXX>
2. Enter meeting number: XXX-XXX-XXX
3. Log in with e-mail address and name

CONNECT TO THE CONFERENCE CALL:

At the designated time, dial (XXX) XXX-XXXX

1. When prompted, enter the audio passcode XXX-XXX-XXX followed by #

The agenda is attached.

Upcoming Meetings

10/18/2007 11:30 am - 1:00 pm
11/16/2007 11:30 am - 1:00 pm
12/13/2007 11:30 am - 3:00 pm

Regards,

Cathy Consumer

Council Web Site

The Web site for NC CACHI is <http://www.nchica.org/CACHI/main.htm>. A Web site is an excellent format to communicate with members, potential members and other interested parties (such as media). The following items may be included in the Web site:

1. Council name, logo
2. Council description / purpose / impetus
3. Council charter
4. Minutes
5. Agendas
6. Contact information
7. Ability to sign up to receive future communications

Important: Some members may not wish to publish their particular healthcare interest. To ensure trust and confidentiality, members should thoroughly read the minutes prior to approval and publication.

Any documentation such as minutes or agendas that are placed on the Web site should be in final format and approved by the consumer group prior to its publication on the Web site.

Other Forms of Communication

There are other forms of communication to help with recruiting, marketing, and outreach to other consumer groups, policymakers, researchers and interested parties. These include:

1. Brochures about speakers or other issues of concern, such as security and privacy or PHRs
2. Media outreach to increase the level of awareness of the group's activities
3. Announcements or news releases about important events or speakers
4. White papers about topics of interest (these could be generated by the Resource Panel based on member input)
5. Focus groups to learn more from specific parties of interest such as consumers, providers or vendors
6. Surveys to gather information from members or other parties of interest
7. Programs, workshops, etc. to further inform other parties of interest

CONSUMER RESOURCES

A library of articles, consumer surveys, studies and lists of Web sites should be made available and maintained for the consumer group's discussions, if appropriate. The NC CACHI list is as follows (can be found at <http://www.nchica.org/CACHI/resources.htm>):

Resource Library

American Health Information Community (AHIC) Consumer Empowerment Group
<http://www.hhs.gov/healthit/ahic/consumer/>

Agency for Healthcare Research and Quality (AHRQ) Health Information Technology
<http://healthit.ahrq.gov>
[AHRQ Privacy and Security Toolkit](#)

American Medical Association (AMA) Statement on Patient Confidentiality
<http://www.ama-assn.org/ama/pub/category/4610.html>

eHealth Initiative
[Secure EHI Exchange: A Guide for Consumers](#)
[Survey of Consumers on EHI Exchange](#)

Health Privacy Project
<http://www.healthprivacy.org/>

Healthcare Information and Management Systems Society (HIMSS)
<http://www.himss.org>

HIT Dashboard
<http://www.hitdashboard.com/default.aspx>

National Coalition of Mental Health Professionals and Consumers (NCMHPC)
<http://www.thenationalcoalition.org/CPH.htm>

National Conference of State Legislatures (NCSL)
<http://hit champions.org/>

North Carolina Institute of Medicine Task Force on Health Literacy (NC IOM)
http://www.nciom.org/projects/health_literacy/health_literacy.html

Patient Advocate Foundation
<http://www.patientadvocate.org/index.php>

Patient Privacy Rights
<http://www.patientprivacyrights.org/site/PageServer>

State RHIO Consensus Project
<http://www.staterhio.org/>