

NC HISPC Privacy and Security Public Policy Toolkit Framework

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Privacy & Security Solutions for Interoperable HIE
RTI International

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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

NCHICA would like to acknowledge the following members of the NC HISPC team for their contributions to the Public Policy Campaign Toolkit:

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Roy Wyman, Jr., William Mullens

EXECUTIVE SUMMARY

Historical Background

[insert background]

Why Health IT Policy Change is Critical

- *Topics to include*
 - Aging population
 - Number of uninsured
 - Medication safety
 - US healthcare vs. rest of world → global economy
 - “The role of local efforts is critical in improving the quality and safety of healthcare in the US,” said Janet Marchibroda, Chief Executive Officer of eHealth Initiative. “In addition to national focus on both standards and financing to address sustainability, both leadership and collaboration among multiple stakeholders at the community level is needed, to build social capital for information sharing, build business cases for sharing the costs of an infrastructure that benefits everyone, and facilitate the flow of the clinical information needed for care delivery, much of which resides locally.”¹

¹ Marchibroda, Janet. “eHealth Initiative Releases Results of 2007 Survey on Health Information Exchange.” Dec. 19, 2007.

**North Carolina Health Information Security and Privacy Collaboration
Public Policy Campaign Toolkit**

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PURPOSE OF THE PUBLIC POLICY CAMPAIGN TOOLKIT

The purpose of the Public Policy Campaign Toolkit is to provide a trusted framework for organizations to heighten public policymakers' awareness of the benefits and importance of health information technology (health IT). The objective is to empower public policymakers with this knowledge, so that they can, in turn, help consumers understand the rewards and risks associated with the use of electronic health information in our health and care system.

HOW TO USE THE PUBLIC POLICY CAMPAIGN TOOLKIT

This toolkit contains two components:

1. The **Executive Summary** describes how this project was formed and funded and its objectives.
2. The **Public Policy Campaign Toolkit** includes prescriptive guidance and resources to assist interested organizations in developing and/or augmenting their public policy outreach strategy and messaging.

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

BUILDING THE FOUNDATION

- *Topics to include*
 - Clearly establish organization's position (i.e. advocating vs. lobbying)
 - Craft an initial message/concept the entire organization supports
 - Identify best practices and lessons learned from other organizations who have conducted similar campaigns (ex. Pennsylvania eHealth Initiative, HIMSS)

COLLABORATION STRATEGY

- *Topics to include*
 - How to identify potential collaborators and secure their support for your efforts
 - How to recruit thought leaders and subject matter experts for your cause
 - Working together to create a joint message/concept that all involved support
 - Bipartisan in nature
 - Determining responsibilities, assigning roles and allocating time
 - Example of invitation to collaborate/participate (similar to NC CACHI invitation below)

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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(NCHICA)

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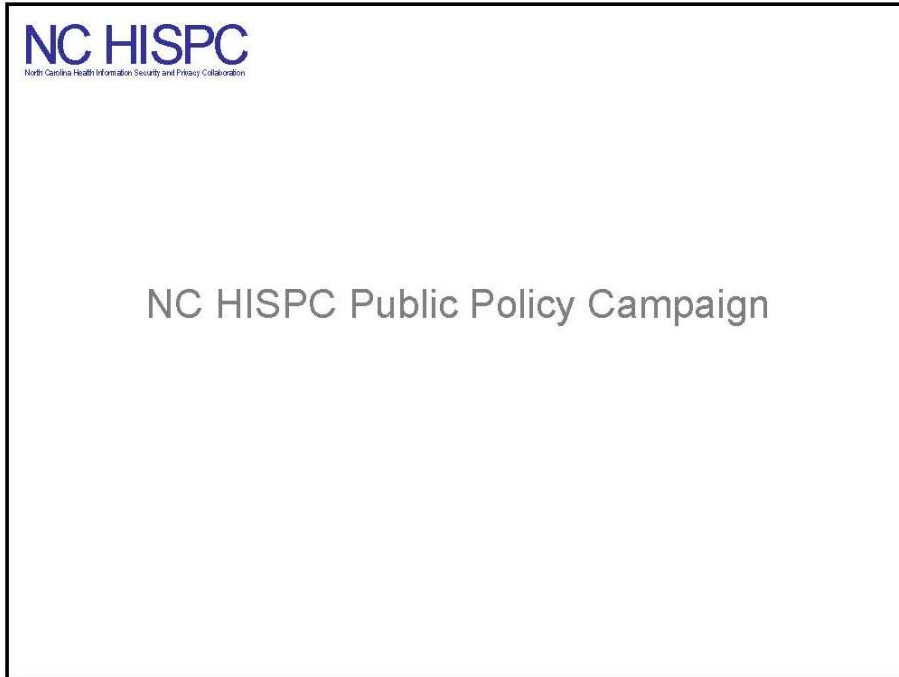
TACTICAL COORDINATION OF CAMPAIGN

- *Topics to include*
 - Coordinate and reserve a date with the NC legislature
 - Seating (suggestion is to seat by districts)
 - Create the agenda
 - Outline speakers and discussion topics
 - Identify potential speakers and conduct outreach
 - Define success goals
 - Number of stakeholders per district
 - Number of public policymakers
 - Message dissemination
 - Create a public policymakers invitation that includes:
 - Organizational backgrounder
 - Goal statement (educate public policymakers on health IT)
 - List of stakeholders

COMMUNICATION TOOLS

Public Policy Outreach Campaign

NC HISPC Public Policy Campaign Example



1. Distillation and Core Messaging

NC HISPC Audience

US Congress

- US Senate
 - Richard Burr
 - Elizabeth Dole

- US House (13 districts)
 - G.K. Butterfield, 1
 - Bob Etheridge, 2
 - Walter B. Jones, 3
 - David Price, 4
 - Virginia Foxx, 5
 - Howard Coble, 6
 - Mike McIntyre, 7
 - Robin Hayes, 8
 - Susan Wilkins Myrick, 9
 - Patrick T. McHenry, 10
 - Heath Shuler, 11
 - Melvin L Watt, 12
 - Brad Miller, 13

US Congress and NC candidates for public office

- This includes governor and lieutenant governor

US Congress and NC Government staff

NC HISPC Audience - Cont'd

NC General Assembly

- NC House (120 districts)
 - Alma Adams, 58
 - Martha B. Alexander, 106
 - Lucy T. Allen, 49
 - Cary D. Allred, 64
 - Marilyn Avila, 40
 - Jeff Barnhart, 82
 - Larry Bell, 21
 - Curtis Blackwood, 68
 - Dan Blue, 33
 - John M. Blust, 62
 - Alice L. Bordsen, 63
 - Joe Boylan, 52
 - R. Van Braxton, 10
 - William D. Brisson, 22
 - Larry R. Borwn, 73
 - Harold J. Brubaker, 78
 - Angela R. Bryant, 7
 - Becky Carney, 102
 - Walter G. Church, Sr., 86
 - Debbie A Clay, 110
 - George G. Cleveland, 14
 - Lorene Coates, 77
 - Nelson Cole, 65
 - Linda Coleman, 39
 - Tricia Ann Cotham, 100
 - James W. Crawford, Jr., 32
 - W. Pete Cunningham, 107
 - William A. Current, Sr., 109
 - Bill Daughtridge, 25
 - N. Leo Daughtry, 26
 - Margaret Highsmith Dickson, 44
 - Jerry C. Dockham, 80
 - Nelson Dollar, 36
 - Beverly M. Earle, 101
 - Bob England, M.D., 112
 - Bill Faison, 50

NC HISPC Audience - Cont'd

- NC House
 - Jean Farmer-Butterfield, 24
 - Susan C. Fisher, 114
 - Dale R. Folwell, 74
 - Phillip Frye, 84
 - Ken R. Furr, 67
 - Pryor Gibson, 69
 - Mitch Gillespie, 85
 - Rick Glazier, 45
 - Bruce Goforth, 115
 - Melanie Wade Goodwin, 66
 - W. Robert Grady, 15
 - Jim Gulley, 103
 - Joe Hackney, 54
 - R. Phillip Haire, 119
 - Larry D. Hall, 29
 - Jim Harrell, III, 90
 - Ty Harrell, 41
 - Pricy Harrison, 57
 - Dewey L. Hill, 20
 - Mark K. Hilton, 96
 - Hugh Holliman, 81
 - Bryan R. Holloway, 91
 - George M. Holmes, 92
 - Julia C. Howard, 79
 - Pat B. Hurley, 70
 - Verla Insko, 56
 - Maggie Jeffus, 59
 - Earl Jones, 60
 - Linda P. Johnson, 83
 - Carolyn H. Justice, 16
 - Carolyn K. Justus, 59
 - Linda P. Johnson, 83
 - Ric Killian, 105
 - Joe L. Kiser, 97
 - James H. Langdon, Jr., 28
 - David R. Lewis, 53
 - Jimmy L. Love, Sr., 51
 - Marvin W. Lucas, 42
 - Paul Luebke, 30
 - Grier Martin, 34
 - Mary E. McAllister, 43
 - Daniel F. McComas, 19

NC HISPC Audience - Cont'd

- NC House
 - Pat McElraft, 13
 - Wm. C. "Bill" McGee, 75
 - Marian N. McLawhorn, 9
 - Henry M. Michaux, Jr., 31
 - Annie W. Mobley, 5
 - Tim Moore, 111
 - Wil Neumann, 108
 - Bill Owens, 1
 - Earline W. Parmon, 72
 - Louis M. Pate, Jr. 11
 - Garland E. Pierce, 48
 - Ray Rapp, 118
 - Karen B. Ray, 95
 - Deborah K. Ross, 38
 - Ruth Samuelson, 104
 - Drew Saunders, 99
 - Mitchell S. Setzer, 89
 - Timothy L. Spear, 2
 - Paul Stam, 37
 - Edgar V. Starnes, 87
 - Fred F. Steen, II, 76
 - Bonner L. Stiller, 17
 - Ronnie Sutton, 47
 - Cullie M. Tarleton, 93
 - Charles C. Thomas, 116
 - Thom Tillis, 98
 - Joe P. Tolson, 23
 - Russell E. Tucker, 4
 - Alice Graham Underhill, 3
 - William L. Wainwright, 12
 - Trudi Walend, 113
 - R. Tracy Walker, 94
 - Edith D. Warren, 8
 - Ray Warren, 88
 - Jennifer Weiss, 35
 - Roger West, 120
 - Laura I. Wiley, 61
 - W. A. (Winkie) Wilkins, 55
 - Arthur Williams, 6
 - Larry Womble, 71
 - Michael H. Wray, 27
 - Thomas E. Wright, 18
 - Douglas Y. Younge, 46

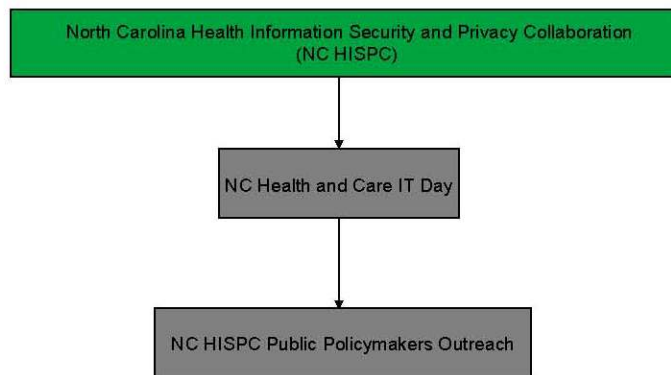
NC HISPC Audience - Cont'd

- NC General Assembly
 - NC Senate (50 districts)
 - Marc Basnight, 1
 - Jean Preston, 2
 - Clark Jenkins, 3
 - Ed Jones, 4
 - John H. Kerr III, 5
 - Harry Brown, 6
 - Doug Berger, 7
 - R.C. Soles, Jr., 8
 - Julia Boseman, 9
 - Charles W. Albertson, 10
 - A.B. Swindell, 11
 - Fred Smith, 12
 - David F. Weinstein, 13
 - Vernon Malone, 14
 - Neal Hunt, 15
 - Janet Cowell, 16
 - Richard Stevens, 17
 - Bob Atwater, 18
 - Tony Rand, 19
 - Floyd B. McKissick, Jr, 20
 - Larry Shaw, 21
 - Harris Black, 22
 - Eleanor Kinnaird, 23
 - Tony Foriest, 24
 - William R. Purcell, 25
 - Phil Berger, 26
 - Kay R. Hagan, 27
 - Katie G. Dorsett, 28
 - Jerry W. Tillman, 29
 - Don East, 30
 - Peter S. Brunstetter, 31
 - Linda Garrou, 32
 - Stan Bingham, 33
 - Andrew C. Brock, 34

NC HISPC Audience - Cont'd

- NC Senate
 - W. Edward (Eddie) Goodall, 35
 - Fletcher L. Hartsell, Jr, 36
 - Daniel G. Clodfelter, 37
 - Charlie Smith Dannelly, 38
 - Robert Pittenger, 39
 - Malcolm Graham, 40
 - James Forrester, 41
 - Austin M. Allran, 42
 - David W. Hoyle, 43
 - Jim Jacumin, 44
 - Steve Goss, 45
 - Walter H. Dalton, 46
 - Joe Sam Queen, 47
 - Tom Apodaca, 48
 - Martin L. Nesbitt, Jr., 49
 - John Snow, 50

NC HISPC Public Policy Message Framework



NCHICA Sponsored NC Health and Care IT Day

Message

- Improve the state of health and care through informed health IT public policy
- NC Health and Care IT Day participants connect with North Carolina public policymakers in a half-day session on current issues
 - **Coordinate with NCHICA regional meetings**
 - **Coordinate with other collaborators (see next slide)**

Proof Points

- NCHICA charter
- Unbiased views from NC CACHI
- NC CACHI and NCHICA stakeholders
- Map NCHICA stakeholders to representatives

Potential Collaborators (list is not exhaustive)

- Health Management Association
- HIT Law firms
- HIT Vendors
- NC Association of Pharmacists
- NC Association of Free Clinics
- NC DHHS Division of Medical Assistance (Medicaid)
- NC DHHS Division of MH/DD/SAS
- NC DHHS Office of MMIS
- NC Health Information Management Association
- NC Health Systems
- NC HIE Council
- NC HISPC
- NCHICA
- NCHICA/NHIN 2 Governance Council
- NCHIMA / Pitt County Memorial Hospital
- NC Hospital Association
- NC Institute of Medicine
- NC Medical Society
- NC Nurses Association
- NC Psychiatric Association
- NC Psychological Association
- NC State Teachers and Employees Health Plan
- UNC School of Public Health

Next Steps and Timing

- NCHICA to coordinate collaboration meeting for strategy and timeline
 - **Early 2008**
- Coordinate with NCHICA regional meetings

NC HISPC Public Policymakers Toolkit

Message

- NC HISPC educates public policymakers on the importance of electronic health information for consumers who can use it to better manage their own health
- NC HISPC Public Policymakers Toolkit provides a trusted framework for public policymakers to help consumers understand the rewards and risks associated with the use of electronic health information in our health and care system
 - Ensure toolkit is educational vs. lobbying
 - Coordinate with other collaborators

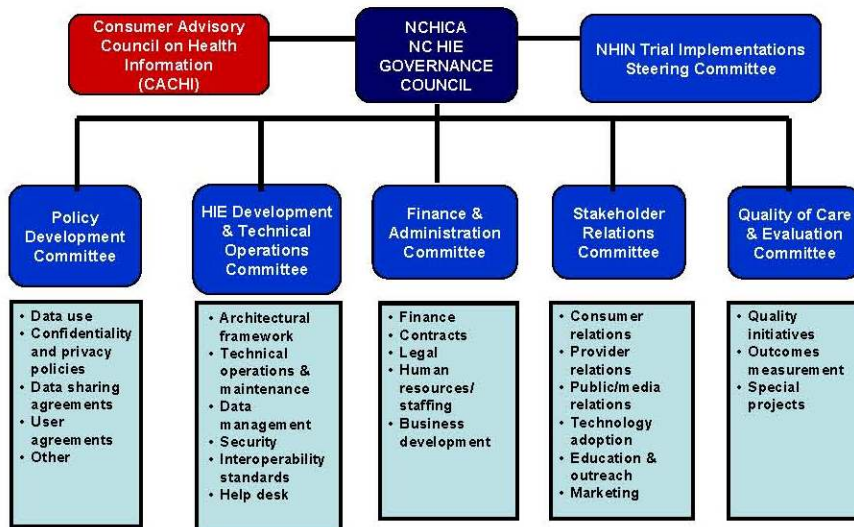
Proof Points

- National and state
 - Hosted consumer awareness meetings with the Markle Foundation, Patient Privacy Rights and Dossia
 - HISPC NC CACHI report
 - NHIN 2 trial implementations
 - Viewed nationally as a potential model by other consumer groups such as Patient Privacy Rights, Health Privacy Project and AHIC Workgroup on Consumer Empowerment
 - Started by NCHICA and supported by NC HISPC
- Trusted resource
 - Formed by NCHICA to be a neutral forum for consumers
 - 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

2. NC Health and Care IT Day Campaign

NCHICA Sponsored NC Health and Care IT Day Campaign

- Objectives
 - Heighten public policymakers' awareness of benefits, risks and importance of health IT
- Target Audience
 - North Carolina state legislative representatives
 - US House and Senate congressional delegation from North Carolina
- Media Audience Segmentation
 - National health IT reporters
 - National general healthcare reporters
 - Statewide consumer reporters



Campaign Process

1. Coordinate and reserve NC Health and Care IT Day date with NC legislature and candidates for public office
 - **Include location**
2. Create NC Health and Care IT Day agenda
 - **In conjunction with collaborators**
 - **Identify potential speakers and conduct outreach**
 - **Outline speaker and discussion topics**
 - **Arrange seating by district**
3. Define success goals
 - **Number of stakeholders per district**
 - **Number of public policymakers**
4. Create a NC government invitation
 - **NC HISPC background**
 - **Collaborators' list of stakeholders**
 - **Goal statement: educate public policymakers on health IT**
5. Create stakeholder invitation for NC Health and Care IT Day
6. Distribute stakeholder and government invitation via email
7. Develop and distribute media alerts and regionally focused news releases

Public Policymakers Toolkit (NC CACHI to lead)

- Toolkit includes
 - **Letter to stakeholders**
 - **Emphasizes the importance of supporting health IT**
 - **Health IT is a bipartisan issue**
 - **NC Health and Care IT Day website button**
 - **Email template**
 - **Quarterly updates on NC**
 - Updates sent via NC CACHI email to policymakers
 - **NC vs. other states on health IT adoption, events, legislation and other important topics**

Other Forms of Communication

There are other forms of communication that can be utilized for 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
3. Announcements or news releases about important initiatives or events
4. White papers about topics of interest
5. Focus groups to learn more from specific parties of interest such as consumers, providers or vendors
6. Surveys to gather information parties of interest
7. Programs, workshops, etc. to further inform public policymakers and their staffs
8. Newsletters and other materials public policymakers can use to disseminate messages about the importance of health IT

PUBLIC POLICY RESOURCES

[insert list of resources]