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## **Dallas NHIN Conference / 5-1-2008**

### **HISPC Consumer Education & Engagement and Provider Education Collaboratives**

### **NHIN / HISPC / SLHIE Joint Conference**

Health Information Security & Privacy  
**COLLABORATION**



### **HISPC Consumer Education & Engagement and Provider Education Collaboratives**

*May 1, 2008*

Dallas, TX

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**Phyllis Albritton**

**HISPC Education & Consumer Engagement Collaborative**

## **Education & Consumer Engagement Collaborative: Goals**

- Consumers are informed about HIE and its progress
- Consumers are engaged in the HIE process
- Consumers know what to expect and how to interact with developed/developing HIE systems

## **Collaborative Strategy (points to consider)**

- Two questions guided the strategy:
  - How do we engage consumers?
  - What do we educate them about?

- Many roads to realization of HIE initiatives but all rely on intimate knowledge of local populations
- Use of literacy and language considerations to allow better “connections” with target populations

## Collaborative Strategy

The strategy of our Collaborative is to advance each state along their current HIE trajectory as well as leverage the expertise and experience of participant states to create a central resource/tool center.

## Education & Consumer Engagement Collaborative: Process

- 8 states each with a set of state projects
- 8 common projects
  - Creation of inventory matrix of existing consumer education/engagement materials and resources
  - Creation of summary document on risks and benefits of HIE
  - Creation of a summary document on FAQs about privacy and security in HIE
  - Development of a glossary/definitions of common HIE and HIT privacy and security terms
  - Creation of two guides: *Patient Rights Under HIPAA* and *Tips to Protect Health Information*
  - Creation of guidelines for how to engage consumers in HIE
  - Identification of methods and resources by which states can have their educational materials translated into multiple languages and literacy levels
  - Development of educational materials for consumers about the specific decisions they will make about whether and to what extent to consent to participate in HIE.

## Common Project 1

- Goal: Creation of inventory matrix of existing consumer education/engagement materials and resources
- Of note: Items will include, for example, HIT architecture type, record type, media, language available, population description and size, analytics, cost and other items.
- Lead/contact info: Peggy Evans, Ph.D, Washington, [PeggyE@qualishealth.org](mailto:PeggyE@qualishealth.org)

## Common Project 2

- Goal: Creation of summary document on risks and benefits of HIE
- Of note: Misunderstanding of how HIE is used will be addressed by describing risks and benefits of technological improvements to the health care system.
- Lead/contact info: Phyllis Albritton, Colorado, [palbritton@pcubedpartners.com](mailto:palbritton@pcubedpartners.com)

## Common Project 3

- Goal: Creation of a summary document on FAQs about privacy and security in HIE
- Of note: Collaborative states will submit FAQs specific to specialty/target populations in their states. Answers will be reviewed by legal experts, refined, and released.
- Lead/contact info: Jerilyn Heinold, M.P.H., Massachusetts, [jheinold@mahealthdata.org](mailto:jheinold@mahealthdata.org)

## Common Project 4

- Goal: Development of a glossary/definitions of common HIE and HIT privacy and security terms
- Of note: Inclusion of existing glossaries and resources, removal of redundancies, selection of high priority/high need terms.
- Lead/contact info: Victoria Wangia, Ph.D., Kansas, [vwangia@kumc.edu](mailto:vwangia@kumc.edu)

## Common Project 5

- Goal: Creation of two guides: *Patient Rights Under HIPAA* and *Tips to Protect Health Information*
- Of note: Creation of pamphlets detailing rights and remedies to be included as part of an education packet for consumers.
- Lead/contact info: Dawn Bonder, J.D., Oregon, [dawn.bonder@state.or.us](mailto:dawn.bonder@state.or.us)

## Common Project 6

- Goal: Creation of guidelines for how to engage consumers in HIE
- Of note: Use of Internet resources, existing consumer committees for distribution to consumer and professional audiences.
- Lead/contact info: Patricia Ruddick, R.N., West Virginia, [pruddick@wvmi.org](mailto:pruddick@wvmi.org)

## Common Project 7

- Goal: Identification of methods and resources by which states can have their educational materials translated into multiple languages and literacy levels
- Of note: Exploration of what data should be evaluated to determine the appropriate literacy level for target populations using research of best practices and discussion with literacy and language experts.
- Lead/contact info: Dawn Bonder, J.D., Oregon, [dawn.bonder@state.or.us](mailto:dawn.bonder@state.or.us)

## Common Project 8

- Goal: Development of educational materials for consumers about the specific decisions they will make about whether and to what extent to consent to participate in HIE
- Of note: Development of consumer consent template for other states including options. Also, the compilation of questions to be used in the development of consent policies.
- Lead/contact info: Ellen Flink, M.B.A., New York, [emf02@health.state.ny.us](mailto:emf02@health.state.ny.us)

## Collaborative State Projects

**Please note that the descriptions, goals and outcomes that follow may only partially represent the efforts and wealth of information for those states. For full descriptions and questions, please contact the leads for each project or subject of interest. Thank you!**

## Education & Consumer Engagement Collaborative: Colorado

- Goal: To educate consumers statewide, in particular the Latino and chronic care communities, and to increase awareness and acceptance of HIE.
- Outcomes/tools: clearinghouse for consumer information on HIE, video presentation, development of physician champions, standardize communication tools for the state.
- Lead/contact info: Phyllis Albritton, Colorado, [palbritton@pcubedpartners.com](mailto:palbritton@pcubedpartners.com)

## Education & Consumer Engagement Collaborative: Georgia

- Goal: To develop a marketing campaign to communicate standard messages to promote trust for HIT and HIE.
- Outcomes/tools: Creation of website for consumer privacy and security educational information.
- Lead/contact info: Alicia McCord-Estes, Georgia, [aestes@dch.ga.gov](mailto:aestes@dch.ga.gov)

## Education & Consumer Engagement Collaborative: Kansas

- Goal: Development of educational materials that raise awareness of HIE/HIT privacy and security issues for use by rural consumers.
- Outcomes/tools: Development of a tool kit and communication/dissemination plan.
- Lead/contact info: Victoria Wangia, Ph.D., Kansas, [ywangia@kumc.edu](mailto:ywangia@kumc.edu)

## Education & Consumer Engagement Collaborative: MA Projects

**Goal: To inform and educate consumers and behavioral health clinicians about HIE for sensitive information by using language and literacy appropriate materials.**

Outcomes/tools: Online, self-directed tutorial, web-based FAQs for sensitive information. Laws and regulations for sensitive information under federal and MA law. Video with subject matter expert panel (e.g., consumer, psychiatrist, primary care physician, pediatrician, and consumer advocate. Development of inventory of PHR choices with special attention to the capture and display of sensitive health information. Guidelines for choosing an appropriate PHR.

Lead/contact info: Jerilyn Heinold, M.P.H., Massachusetts, [jheinold@mahealthdata.org](mailto:jheinold@mahealthdata.org)

## Education & Consumer Engagement Collaborative: New York

- Goal: To help New Yorkers navigate the consent choices they will be required to make in order to participate in HIE.
- Outcomes/tools: Inventory of consent materials including e-forms and brochures. Creation of decision-making paradigm for types of consent. Focus group testing of materials, dissemination and communication strategy development.
- Lead/contact info: Ellen Flink, M.B.A., New York, [emf02@health.state.ny.us](mailto:emf02@health.state.ny.us)

# Education & Consumer Engagement Collaborative: Oregon

- Goal: Develop discussion of privacy issues such as access, control, consent, and secondary uses to inform policies, laws, and business practices.
- Outcomes/tools: Development of common vocabulary. Educational material supporting the existing documentary regarding perceptions of privacy. Creation of Town Hall type meetings to support educational efforts.
- Lead/contact info: Dawn Bonder, J.D., Oregon, [dawn.bonder@state.or.us](mailto:dawn.bonder@state.or.us)

# Education & Consumer Engagement Collaborative: Washington

- Goal: To educate consumers about the consumer-centric health record banking (HRB) model.
- Outcomes/tools: Identification of target audiences, core messages, communication strategies. Development and testing of toolkit. Encouragement of consumer use of health record banking.
- Lead/contact info: Peggy Evans, Ph.D., Washington, [PeggyE@qualishealth.org](mailto:PeggyE@qualishealth.org)

# Education & Consumer Engagement Collaborative: West Virginia

- Goal: Education of seniors, chronic disease patients (diabetes) and rural populations with respect to HIE by using a statewide media campaign.
- Outcomes/tools: Development of website to serve as a clearinghouse for consumer information on HIE and EMRs. Creation of billboards and broadcasts. Identification and encouragement of physician champions by creation of a toolkit for distribution by physicians as well as a video.
- Lead/contact info: Patricia Ruddick ,R.N., West Virginia, [pruddick@wvmi.org](mailto:pruddick@wvmi.org)

# Questions?

- Thank you !
- Jerilyn W. Heinold, M.P.H.  
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