MARYLAND
HEALTH CARE
COMMISSION

# HEALTH INFORMATION TECHNOLOGY

# CONSUMER AWARENESS & EDUCATION BRIEF

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MARYLAND
HEALTH CARE
COMMISSION

# Commissioners

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## Overview

The health care industry is in a state of change. New technologies, legislative changes, rising costs and growing consumer expectations mean that the health care industry needs to think differently about how to build relationships with consumers. The adoption and use of health information technology (health IT) by consumers may empower patients to manage their health and health care by increasing their access to their health information. Engaging consumers has taken a central role in the federal electronic health record (EHR) incentive program[1] as providers are required to demonstrate that their patients have access to their medical records in a timely manner. A system that puts the consumer at the center of health care delivery can improve the well-being of individuals.

Widespread adoption of health IT has the potential to improve the efficiency, quality and effectiveness of health care delivery.[2, 3, 4, 5] National consumer health IT awareness and education efforts have been slow to materialize. Many states are now beginning to explore opportunities to educate the public on health IT. In the fall of 2011, the Maryland Health Care Commission (MHCC) engaged a consulting group, Koss on Care, LLC, to convene a series of consumer focus groups to assess consumer awareness and confidence in electronic health information. The focus groups (focus groups or participants) provided an opportunity to engage consumers, providers, and community based organizations (CBOs) in identifying leading challenges to increasing consumer awareness and education and proposing a practical long-range strategy to build confidence in electronic health information.

Seven consumer focus groups were convened in Charles, Kent, Montgomery, Prince George's, and Somerset counties, and two groups in Baltimore City.[6] In addition, two focus groups were convened with participants from CBOs representing medically underserved populations, and five focus groups were convened with providers in Western Maryland, the Eastern Shore, and Baltimore City.[7, 8] Interviews were also conducted with organizations that operate a health information exchange (HIE). In general, most participants said they need to have a better understanding of health IT before trusting electronic health information. Many participants mentioned that once

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[1] The *Health Information Technology for Economic and Clinical Health Act*, enacted as part of the *American Recovery and Reinvestment Act of 2009*, established the Medicare and Medicaid Electronic Health Record Incentive Program that offers incentive payments to eligible providers and eligible hospitals that adopt a certified electronic health record system and show that they are meaningfully using the system, based on requirements determined by the Centers for Medicare and Medicaid Services. Additional information is available at: http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/index.html?redirect=/EHRIncentivePrograms/.

[2] Institute of Medicine, *Health IT and Patient Safety: Building Safer Systems for Better Care*, 2012. Available at: http://books.nap.edu/openbook.php?record_id=13269.

[3] The New England Journal of Medicine, *Use of Electronic Health Records in U.S. Hospitals*, 360(16), April 2009. Available at: http://www.nejm.org/doi/full/10.1056/NEJMsa0900592.

[4] Annals of Internal Medicine, *Systematic Review: Impact of Health Information Technology on Quality, Efficiency, and Costs of Medical Care*, 144(10), May 2006. Available at: http://www.annals.org/content/144/10/742.full.

[5] Health Affairs, *The Benefits Of Health Information Technology: A Review Of The Recent Literature Shows Predominantly Positive Results*, 30(3), March 2011.

[6] For more information regarding the approach to the consumer focus groups, see Appendix A.

[7] For more information regarding the CBO focus groups, see Appendix B.

[8] For more information regarding the provider focus groups, see Appendix C.

consumers realize the benefits of health IT, they tend to embrace the idea of providers using technology in care delivery.

The federal *Health Information Technology for Economic and Clinical Health* (HITECH) Act of 2009 has invested billions of dollars to accelerate the adoption of health IT. Health information exchanged electronically can benefit patients by enabling providers to have better, faster access to patient information.[9] Health IT can also enable consumers to electronically review their health records, correct and add information to their health record, schedule appointments, order prescription refills, and review health educational materials.[10] The potential benefits of health IT adoption on consumers are expected to emerge gradually over the next five years. The overall lack of health IT awareness by consumers and breaches reported by the media create concern about privacy, security, and misuse of electronic health information. Increasing consumer health IT awareness and education may lessen these concerns.

Consistent themes that emerged from the focus group discussions include: consumers prefer to control who has access to their electronic health information; CBOs are concerned about the risk of electronic health information being lost or stolen; and concern regarding the lack of health IT awareness and education activities in the state. The focus group discussions provided the framework to formulate a strategy to advance consumer awareness and trust of electronic health information in the state. Establishing a Consumer Advisory Council is a practical approach to address challenges related to consumer awareness of health IT, increase consumer outreach and education, and develop a plan for consumers to access their electronic health information.

## Acknowledgements

The MHCC appreciates the assistance of Koss on Care, LLC in convening the focus groups and in drafting the report. The contribution by the focus group participants was instrumental in formulating strategies to increase consumer awareness and trust in health IT. Thanks to Damon Davis from the Office of the National Coordinator for Health Information Technology (ONC) for providing input into the document.

## Limitations

The information included in this brief is limited to the views of the participants. A consistent set of questions was asked at focus group meetings. The questions were planned to guide broad discussion among the participants. Responses to the questions were not intended for analysis in a structured data base and may have been influenced by other participants in attendance at the meetings. A financial impact assessment associated with implementing the recommendations was not included in the work.

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[9] Health Affairs, *Satisfying Patient-Consumer Principles for Health Information Exchange: Evidence From California Case Studies*, 31 (3). March 2012.

[10] Ibid.

## Background

Health information is located across multiple provider settings where paper and electronic patient information is generally not shared electronically. The use of computers to manage health information lags behind most major industries, such as banking, where its use to manage data is almost universal.[11] Challenges around privacy and security, the costs to move from a paper-based system, short-term productivity loss, and issues around standards are a few reasons for the slow adoption of health IT. Broad adoption and use of health IT by providers is expected to eliminate the digital divide that exists today. Currently, most information sharing is primarily through facsimile or paper records. Health IT has the ability to improve patient outcomes by enabling provider access to a consumers' information at the point of care.[12] Consumer trust in health IT is an essential component in building provider support for the electronic exchange of their health information.

Generally, consumers tend to have a trusting relationship with their providers.[13] Health IT may be a new concept to most consumers.[14] In the near future, a provider's adoption of health IT will most likely have a greater influence on the relationship a consumer has with their provider. A 2010 study by the California HealthCare Foundation on innovative uses of technology to improve the quality of care, promote access, and reduce costs noted that a parallel exists between the level of awareness and trust of health IT and the level of consumers' engagement in managing their care.[15] Health IT can assist consumers in taking steps to improve their own health, being more informed about their health care, and asking their providers questions they would not otherwise have asked.[16] Similar findings were published by the eHealth Initiative, which noted the significance between patient engagement in care and the trust of information being securely shared through an HIE.[17] The report suggests one way to build trust is through consumer engagement.

Effective consumer awareness and education programs related to health IT are expected to bolster public trust and confidence, which are both critical to increasing EHR and HIE adoption among providers. Consumer attitudes toward the use of health IT are considerably influenced by concerns around the security of their health information managed by their providers. Privacy and security has been recognized as a significant barrier to the use of electronic health information; sound privacy policies, trusted networks, and oversight and accountability mechanisms are required to build consumer trust.[18] Engaging consumers in health IT requires the use of leading health literacy

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[11] Healthcare Information and Management Systems Society, *Crossing Barriers: A Strategic Approach of E-Health Initiatives*, 22(4). Fall 2008. Available at: http://www.himss.org/content/files/13_Asoh.pdf.

[12] Health Affairs, *The Benefits of Health Information Technology: A Review of the Recent Literature Shows Predominantly Positive Results*, 30(3). March 2011

[13] Health Affairs, *Patients, Physicians, And The Internet*, 19(6). November 2000.

[14] Health Affairs, *A State-Based Approach to Privacy and Security for Interoperable Health Information Exchange*, March/April 2009 28(2).

[15] Lake Research Partners for California HealthCare Foundation, *Consumers and Health Information Technology: A National Survey*, April 2010. Available at: http://www.chcf.org/publications/2010/04/consumers-and-health-information-technology-a-national-survey.

[16] Ibid.

[17] eHealth Initiative, 2*011 Report on Health Information Exchange: Sustainable HIE in a Changing Landscape,* 2011.

[18] Ibid.

principles[19] to develop consumer educational materials that adequately explain the privacy and security protections that safeguard electronic health information.[20]

## Approach

In the fall of 2011, seven consumer focus groups were convened throughout the state to engage consumers in conversations related to awareness, trust and education of health IT. Participants were recruited in partnership with local organizations such as faith based, local health departments, and federally qualified health centers. The participants varied by socioeconomic status, race, ethnicity, age, gender, health status, and literacy level. Participants were asked a series of structured and open-ended questions to encourage a dialogue around the issues related trust in health IT and to propose solutions.[21, 22] The structured questions were intended to serve primarily as the basis for expanding the open-ended dialogue. Participants were also ensured anonymity and where transportation challenges existed participants received a nominal stipend for participation.[23] The table below depicts focus group participation.

**Consumer Focus Groups**

| Meeting Dates | Location | Number of Participants *(n=86)* |
|---|---|---|
| August 29, 2011 | Baltimore City | 13 |
| August 29, 2011 | Baltimore City | 11 |
| August 24, 2011 | Charles County | 11 |
| August 15, 2011 | Kent County | 18 |
| August 11, 2011 | Montgomery County | 12 |
| August 11, 2011 | Prince George's County | 12 |
| August 25, 2011 | Somerset County | 9 |

To gather additional perspectives pertaining to consumer trust of health IT, two focus groups were convened with CBOs that serve the medically underserved, and five provider focus groups were convened throughout Western Maryland, the Eastern Shore and Baltimore City.[24, 25] Interviews with organizations that operate HIEs were also included in the work effort.

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[19] Health literacy refers to the ability to read and comprehend basic concepts related to health. Health literacy principles include ensuring the information is appropriate for users; culturally relevant; easy to use; and in plain language, among other things.

[20] Tripathi M, Delano D, Lund B, Rudolph L., *Engaging Patients for Health Information Exchange,* Health Affiliation (Millwood) 28(2). 2009.

[21] The *Moderator's Guide* is available in Appendix D.

[22] The *Consumer Survey* is available in Appendix E.

[23] For more information regarding the approach to the consumer focus groups, see Appendix A.

[24] For more information regarding the CBO focus groups, see Appendix B.

[25] For more information regarding the provider focus groups, see Appendix C.

## Key Focus Group Findings and Proposed Solutions

### Building Consumer Awareness and Trust

*Challenges:*

- Building trust among consumers with limited access to technology and mixed views about exchanging electronic health information.
- Conveying the value of HIE in an easy to understand and accessible manner that will increase consumer interest, trust, and understanding of electronic health information.
- Developing sufficient and readily understood information for all population segments about how electronic health information will be accumulated, accessed, used, shared and protected.
- Creating educational resources that help address comprehension challenges, including limited English proficiency, limited literacy, limited health literacy, and limited technology literacy.

*Proposed Solutions*

<u>Develop communication materials that focus on unique literacy needs.</u> Educational materials should be produced in English and Spanish, at a minimum. Resolving challenges around comprehension of complex health terminology can be reduced by defining health care terms and concepts and crafting material for unique subpopulations using appropriately targeted reading levels.

<u>Target the least trusting populations initially in building awareness and trust.</u> Direct and trusted communication mechanisms should be used for outreach efforts. Fostering consumer understanding of the value of sharing electronic health information should be a priority with most subpopulations.

<u>Convene in-person education forums with the select subpopulations.</u> As consumers trust their health care providers, these providers should collaborate with other stakeholders to identify organizations that are willing to participate in educating subpopulations that tend to be the least trusting.

### Implementing Consumer Outreach and Education

*Challenges:*

- Appropriately messaging what HIE is, the impact on care delivery when information is exchanged electronically, and how privacy and security will be protected.
- Publicizing entities involved in electronic health information and the role of the State.
- Explaining in general how providers access, use, and disclose electronic health information.
- Identifying consumer risks and benefits of electronic health information.

*Proposed Solutions*

Develop programs for consumers aimed at demonstrating the value of HIE in care delivery, coordination, and improved outcomes. Provide examples of how technology can be used to enhance patient care. Explain the role of consumers in ensuring their electronic health information is accurate and the impact of their provider participating in HIE.

Inform consumers about existing HIE technology capabilities and what is planned for the future. HIE is evolving and consumers need to know what information can currently be exchanged and to whom the information can be disclosed. Present information in a way that explains how increased HIE capabilities will benefit consumers.

### Developing Consumer HIE Access

*Challenges:*

- The availability of technology that enables consumer access to their electronic health information.
- Resolving policy challenges around HIEs disclosing information to consumers.
- Educating consumers on best practices to ensure that electronic health information is appropriately used by consumers.
- Addressing provider reluctance to trust electronic health information where consumers have access to the data.

*Proposed Solutions*

Develop communication material for consumers around access to their electronic health information. The material should include information about the future of HIE where consumers will be able to control who accesses their data. Include best practice guidance for protecting information stored on personal electronic devices.

Educate consumers on the impact of granular control of their electronic health information. Describe the value and potential impact of managing provider access to their electronic health information. Include education around their right to exercise their choice in participating in HIE and the consequences of not participating.

Identify opportunities to engage consumers as advocates for health IT adoption. Consumer engagement can influence technology adoption among providers. Educating consumers on the way they can encourage their providers to become active participants in health IT will impact the adoption rate.

## A Strategy to Increase Consumer Awareness and Trust

### Establish a Consumer Advisory Council

The focus groups were valuable in identifying issues around health IT that impact consumers. Participants' feedback suggests that a long range strategy to engage consumers and solve issues about awareness and trust is needed. A Consumer Advisory Council (Council) is a practical approach to address the challenges in building consumer awareness and trust in the use of health

IT. The MHCC is responsible for advancing health IT statewide and adopting regulations for the privacy and security of health information exchanged through HIEs in the state and well positioned to convene the Council. The Council should include broad stakeholder representation and is envisioned to have about eight members and meet quarterly.

The primary task of the Council is to identify implementable approaches to increase consumer knowledge of health IT. The Council will also propose strategies aimed at addressing consumer concerns of trust in electronic health information, privacy and security, data integrity, and access. Recommendations will be formulated that take into consideration various existing health IT-related initiatives such as:

<u>The MHCC HIE Policy Board</u>

In December of 2009, the MHCC HIE Policy Board (Policy Board) was convened as an advisory group with oversight authority to establish the policies that govern the statewide HIE. The members were selected based upon their expertise, consideration regarding the breadth of stakeholder representation, and a strong consumer background. The Policy Board's separation of responsibilities assures participation by the public in both policy development and operational oversight. House Bill 784, *Medical Records – Health Information Exchanges* (HB 784), signed into law on May 19, 2011, requires the MHCC to adopt regulations for the privacy and security of protected information exchanged through an HIE.[26] MHCC takes into consideration the Policy Board recommendations when drafting these regulations.

<u>The private non-profit statewide HIE</u>

In the summer of 2009, the MHCC competitively selected the Chesapeake Regional Information System for Our Patients to build a statewide HIE. The statewide HIE enables physicians and hospitals to share electronic health information between appropriately authorized and authenticated providers. Once fully developed, the statewide HIE will assure that providers have access to information at the time and place of care to improve treatment, prevent errors, and reduce health care costs. The statewide HIE will also help gather information to improve disease surveillance, to better our understanding of what clinical treatments work, and to shape practice guidelines. The current governance model includes a Board of Directors that considers input from four advisory boards: Clinical, Finance, Exchange Technology, and Small Practice.

<u>Provider and payer HIEs</u>

Payers that support innovative care delivery models, such as medical homes, are well positioned to exchange health information electronically. Accountable care organizations that emerge as a result of health care reform are likely to develop data sharing models independent of the consolidated effort by state and private consortia to implement a statewide data sharing utility. Organizations that act as community HIEs will eventually offer connectivity to the statewide HIE.

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[26] As defined in HB 784, *Medical Records – Health Information Exchanges.*

## Council Activities

The Council will explore opportunities to develop consumer awareness initiatives that will provide an increased understanding of electronic health information. As part of its work, the Council will consider effective health IT awareness and education programs that include the following subpopulations:

- Sensitive health conditions (HIV, substance abuse, mental health, etc.);
- English as a second language;
- Low income;
- African American with low income (both rural and urban);
- Rural;
- Homeless;
- Low literacy levels (reading, health, and technology);
- Physical disabilities; and
- Safety concerns (e.g., domestic violence).

Ideally, programs proposed by the Council will lead to consumer awareness and education initiatives that result in improvements in quality, care coordination, and health outcomes. The Council will develop a strategy that is phased over several years.

### Develop a consumer awareness and education program blueprint (blueprint)

The Council will develop a blueprint that can be used to guide the development of a statewide awareness and education program aimed at increasing consumer awareness and trust in HIE. Developing the blueprint will require input from a broad range of stakeholders, such as consumer advocacy organizations, providers, and HIEs. The Council will consider existing resources, such as the ONC Consumer Education and Engagement Toolkit.[27, 28] The blueprint will provide guidance to the MHCC on strategies to engage payers and employers in communicating the value of health IT.

The blueprint will include a three year phased implementation approach to initiatives such as the following:

- What are health IT, HIE, EHRs, and personal health records?[29]

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[27] The ONC convened a collaborative of eight states to develop templates, tools, and processes that highlight the risks and benefits, as well as address common consumer concerns, with a focus on using plain language principles. Materials developed by the collaborative have been tailored to the unique concerns of diverse demographic groups, including urban and rural populations, racial and ethnic groups, consumers with varied literacy levels, and specific populations such as those with mental health or chronic health conditions. The toolkit is available online at: http://healthit.hhs.gov/portal/server.pt?open=512&objID=1280&PageID=16051&mode=2&cached=true.

[28] Health Information Security and Privacy Collaboration, *Kansas State Project Communication Plan*, March 2009. Available online at: http://healthit.hhs.gov/portal/server.pt/gateway/PTARGS_0_10779_872279_0_0_18/CEE_Plan_KS_Communication_with_all_apps.pdf.

[29] Generally, a personal health record (PHR) is a tool that enables consumers to maintain their health information electronically. PHRs allow patients to store, reference, manage, and share their health information. A PHR may be a paper or electronic-based system that contains health information, such as family medical history, insurance coverage, demographic data, immunizations, prescribed medications, diagnosed diseases or conditions, and diagnostic exams or surgical procedures.

- What are the benefits and risks of digitizing and exchanging electronic health information?
- What consumer information is stored and exchanged electronically?
- How will technology maintain the privacy and security of electronic health information?
- How will electronic health information be used and by whom?
- What control does the consumer have over his or her electronic health information?
- How is health IT evolving and how it is expected to impact consumers in the future?

## Remarks

Increased consumer awareness and education can lead to greater consumer confidence in health IT. Providers are moving away from paper-based silos of storing health information to an environment where patient information is maintained and shared electronically. As health IT begins to move slowly toward a critical mass of adoption, consumer support is necessary to reform the way the health care system operates. Widespread adoption of health IT addresses a critical need to have information follow patients to support care delivery. Initiatives aimed at increasing consumer awareness and education will help ensure that consumers are able to be more involved in their care. A Council to address consumer awareness and education challenges will increase consumers' use of health IT and ability to maintain their health information, enabling consumers to play a more centralized role in their health care.

# Appendix A: Consumer Focus Groups

### Recruitment for Consumer Focus Group Participation

Organizations with connections to medically underserved populations were asked for their assistance in recruiting consumers. Support from these organizations centered on recruiting from among their community members or agency clients; scheduling the groups and reminding participants about dates and times; and hosting the group at their facility by providing a conference room to comfortably conduct the consumer focus group. The participant recruiting invitation explained that the focus groups' purpose was to discuss health IT.

### Consumer Focus Group Participation

The seven focus groups that were convened consisted of about 13 participants in each session, with individuals that represented subpopulations of the medically underserved. Six of the seven counties where the focus groups were held have residents who demonstrate multiple characteristics of the underserved population in Maryland. Two of the seven focus groups were conducted in Spanish. The names of most participating organizations were purposely omitted.

**Consumer Focus Groups**

| County | Targeted Focus Group Participants |
|---|---|
| Baltimore City | Sensitive health information |
| Baltimore City | Low income |
| Charles | Chronic conditions |
| Kent County | Caregivers and family of chronically ill |
| Montgomery | Chronic conditions (conducted in Spanish) |
| Prince George's | Caregivers and family, or chronically ill (conducted in Spanish) |
| Somerset | African American |

### Consumer Focus Group Demographics

At the conclusion of each focus group, participants were asked to complete an optional informal survey to capture demographic information. Roughly 85 of the 86 consumer focus group participants completed the survey and findings are detailed in the following table.

**Consumer Demographics**

| | Consumer Focus Groups | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| County | Baltimore City First Session | Baltimore City Second Session | Charles | Kent | Montgomery | Prince George's | Somerset | Total |
| Participants in Survey | 13 | 11 | 11 | 17 | 12 | 12 | 9 | 85 |
| 1. Gender: | | | | | | | | |
| Male | 3 | 6 | 6 | - | 3 | 4 | 7 | 29 |
| Female | 10 | 5 | 5 | 17 | 9 | 8 | 2 | 56 |

**Consumer Focus Groups**

| County | Baltimore City First Session | Baltimore City Second Session | Charles | Kent | Montgomery | Prince George’s | Somerset | Total |
|---|---|---|---|---|---|---|---|---|
| 2. Age: | | | | | | | | |
| 18–24 | 4 | 1 | 1 | - | - | - | 1 | 7 |
| 25–34 | - | 2 | - | - | | 2 | 3 | 7 |
| 35–44 | 1 | | 1 | 1 | 1 | 7 | 1 | 12 |
| 45–54 | 4 | 7 | 2 | 2 | 2 | - | 3 | 20 |
| 55–64 | 3 | 1 | 6 | 3 | 5 | 3 | | 21 |
| 65–74 | 1 | - | 1 | 5 | 4 | - | 1 | 12 |
| 75+ | - | - | - | 6 | - | - | - | 6 |
| *3. Last grade level completed: | | | | | | | | |
| 8th grade or lower | - | - | - | - | 1 | 3 | 2 | 6 |
| Some high school | - | 3 | 1 | - | 2 | - | 2 | 8 |
| High school or GED | 6 | 1 | 6 | 4 | 2 | 3 | 5 | 27 |
| Some college or 2-year degree | 4 | 6 | 2 | 4 | 3 | 5 | - | 24 |
| 4-year degree | 1 | - | 2 | 6 | 2 | - | - | 11 |
| More than a 4-year college degree | 2 | 1 | | 3 | 2 | 1 | - | 9 |
| *4. Yearly household income: | | | | | | | | |
| Less than $22,000 | 6 | 9 | 7 | 5 | 9 | 10 | 7 | 53 |
| Between $22,000 and $66,000 | 5 | 1 | 2 | 7 | - | 2 | 2 | 19 |
| More than $66,000 | 1 | 1 | 1 | 3 | - | - | - | 6 |
| *5. You are: | | | | | | | | |
| American Indian or Alaskan Native | - | - | - | - | - | - | - | 0 |
| Asian | - | - | - | - | - | - | - | 0 |
| Black or African American | 12 | 7 | 2 | 5 | - | - | 8 | 34 |
| White or Caucasian | | 4 | 9 | 12 | - | - | 1 | 26 |
| *6. You are: | | | | | | | | |
| Hispanic or Latino | 2 | 1 | 1 | - | 12 | 12 | - | 28 |
| Not Hispanic or Latino | 6 | 7 | 8 | 16 | - | - | 5 | 42 |
| *7. In the past two years, number of different visits with health care providers: | | | | | | | | |
| 0 | - | - | - | 1 | 1 | 3 | - | 5 |
| 1–3 | 5 | 2 | 3 | 2 | 2 | 5 | 2 | 21 |
| 4–6 | 3 | | 3 | 6 | 4 | 2 | 2 | 20 |
| 7 or more | 4 | 8 | 5 | 8 | 5 | 2 | 2 | 34 |
| *8. In the past two years, number of different health care providers in different offices visited: | | | | | | | | |
| 0 | 3 | 1 | | | - | 1 | 1 | 6 |
| 1–3 | 7 | 7 | 8 | 5 | 5 | 8 | 4 | 44 |

## Consumer Focus Groups

| County | Baltimore City First Session | Baltimore City Second Session | Charles | Kent | Montgomery | Prince George's | Somerset | Total |
|---|---|---|---|---|---|---|---|---|
| 4–6 | 2 | 2 | 1 | 3 | 2 | - | 1 | 11 |
| 7 or more | - | - | 1 | 7 | 5 | 3 | 1 | 17 |
| *9. Responsible for health care of other? | | | | | | | | |
| Yes | 6 | 1 | 2 | 14 | 6 | 12 | 6 | 47 |
| No | 6 | 9 | 9 | 3 | 6 | - | 1 | 34 |
| *10. Do you or someone in your family have a long-term health condition? | | | | | | | | |
| Yes | 9 | 9 | 9 | 17 | 12 | 5 | 4 | 65 |
| No | 3 | 1 | 2 | 0 | - | 7 | 3 | 16 |
| *11. Do you have health insurance? | | | | | | | | |
| Yes | 9 | 10 | 2 | 17 | - | 2 | 5 | 45 |
| No | 3 | - | 9 | - | 12 | 10 | 2 | 36 |
| *12. Do you use a cell phone daily or almost every day? | | | | | | | | |
| Yes | 10 | 10 | 7 | 13 | 9 | 9 | 6 | 64 |
| No | 2 | - | 3 | 4 | 3 | 3 | 1 | 16 |
| *13. Do you use the Internet daily or almost every day? | | | | | | | | |
| Yes | 8 | 6 | 6 | 12 | 7 | 7 | 4 | 50 |
| No | 4 | 4 | 5 | 5 | 5 | 5 | 3 | 31 |

*Note: Not all questions received a 100 percent response from participants; these questions are marked with an asterisk (*) in the chart.*

# Appendix B: Community Based Organization Focus Groups

## Recruitment for CBO Participation

To supplement the consumer focus group findings and to explore how community based organizations (CBOs) might play a role in consumer outreach and education, two focus groups were convened. CBOs that represented constituents or members from underserved populations were selected for participation.

These focus groups had two main goals: (1) to understand health information exchange outreach and education needs of the CBOs' members, and (2) to identify ways the CBOs could play a role in HIE outreach and education. CBOs were invited to participate in focus groups to determine:

- Individual consumers' knowledge and preferences regarding the target HIE topics;
- Consumer health advocacy and CBOs' perspectives on their members and the organizations' potential roles in outreach and education; and
- Providers' perspectives on consumers and input on their roles and challenges regarding all three project topics.

## CBO Focus Group Participation

The three CBO focus groups consisted of representatives from about 20 organizations, including four state chapters of disease organizations, five consumer advocacy organizations, four support an advocacy services for the underserved, three county libraries from underserved areas, two public libraries, and one county health department. CBO focus groups were convened in Kent County and Baltimore City. The following table details the CBO focus group participants.

**CBO Focus Groups**

| Organization | Focus Group Location |
|---|---|
| National Alliance on Mental Illness | Kent |
| The Parents' Place of Maryland | Kent |
| Maryland Legal Services Corporation | Kent |
| Alzheimer's Association | Kent |
| Maryland Department of Aging | Kent |
| Kent County Public Library | Kent |
| Caroline County Public Library | Kent |
| Somerset County Health Department | Kent |
| University of Maryland Health Sciences and Human Services Library | Baltimore City |
| National Network of Libraries of Medicine | Baltimore City |
| Maryland Parity Project – Mental Health Association of Maryland | Baltimore City |
| Healthcare for the Homeless, Inc. | Baltimore City |
| Catholic Charities of Baltimore | Baltimore City |
| Washington County Library | Baltimore City |

| Organization | Focus Group Location |
|---|---|
| Maryland Library Association | Baltimore City |
| American Diabetes Association | Baltimore City |
| Maryland Network Against Domestic Violence | Baltimore City |
| Maryland Women’s Coalition for Health Care Reform | Baltimore City |
| American Heart Association | Baltimore City |
| Baltimore HealthCare Access, Inc. | Baltimore City |

# Appendix C: Provider and HIE Focus Groups

Identifying practical strategies to educate consumers and assess the level of consumer interest requires insight from health care providers. Stakeholder input is critical to eliciting feedback so that strategies can be developed that can be implemented within a realistic and practical timeframe.

### Recruitment for Provider Focus Group Participation

The objectives for the recruitment of the provider focus groups were to ensure broad geographical representation. Recruitment also sought to include participants located in areas with higher percentages of underserved and uninsured populations

Representation in the provider focus groups sought to include:

- Physicians as well as mid-level providers (such as nurse practitioners);
- Providers with varying levels of technology literacy and usage;
- Providers from multiple specialties, such as primary care, cardiology, oncology and endocrinology;
- Input from long-term care and home health providers; and
- Providers who are treating Medicare and Medicaid patient populations.

### Focus Group Participation

A total of five provider focus groups were held throughout the following locations: Western Maryland, the Eastern Shore and Baltimore City. A defined set of questions specific to health IT awareness, trust, outreach, education, access and control were developed. Providers in the five focus groups included small and larger physician practices, federally qualified health centers, community hospitals, and health systems. Some participants were currently exchanging health information electronically, and some participants were using EHRs, while other participants were using paper-based medical records.

## Appendix D: Consumer Focus Group Moderator's Guide

### Introduction

Thank you very much for coming today to participate in this discussion group. My name is _________, and this is ___________. We are here today to discuss health information technology – the use of computers to share information among doctors and hospitals. Health information technology includes electronic health records (EHR) and health information exchange (HIE) that will be used to communicate health care information to and from your doctor or health care provider. Do not worry if you are not too familiar with those things – or have not even heard of them yet! We'll be explaining and discussing them in our group today.

We will be here for about an hour and a half. During that time I will ask questions and _______ will take some notes. For some questions, we will ask for volunteers to answer, and sometimes we will go around the table so everyone has a chance to talk. We will be audio taping the group so that the team can go back and listen to your ideas and opinions. We will not use your last name in our report of today's discussion; in fact, we are not even going to ask for your last name.

What you say is very important to us. Do not worry about being right. There are no wrong answers! We want your honest opinions, and we want to hear whatever you have to say. Everyone can have a different view and that is ok.

To help the discussion go smoothly we would like you to write your first name on these cards. We are also going to give you paper and a pen in case you want to write anything down.

*[Hand out cards, paper and pens.]*

If you need to get up to stretch or get refreshments or use the restroom during the hour, go ahead and do that. The refreshments are ______. Restrooms are located_____. Before we start, does anyone have questions?

### Part I: Awareness and Trust (Questions 1 – 8)

We will begin by making a list of the ways we get information about health now.

*(Note: The following questions were intended to serve as a framework to encourage open dialogue among the participants.)*

1. How do you prefer to get most of your information about your and your family's health?

*[Leader makes the list on the chart paper as participants suggest items for list]*

*[Possible follow up questions for discussion]*

   a. Do you get health information when you want it?
   b. How easy is it to understand the information you get?

2. Which of those on the list do you trust the most to give you health information? For example, if you or someone you know had a serious illness, which would you consult to find out about the illness and the different ways it can be treated? [Probe]

3. How many of you have ever used a computer or cell phone to find health information on the Internet? *[Show of hands]*

*[Possible follow up:*

- *If you did not raise your hand, tell me:*
- *Do you have access to the Internet through a computer or a cell phone?*
- *If you have access to the Internet, did you choose not to use the Internet?*
- *Do you use the Internet, although you do not use the Internet to look for health information?*
- *And for those of you who did raise your hands, how would you rate your ability to use the Internet this way? Are you a beginner, an intermediate or an expert?]*

4. Tell me a little about using the Internet for health information. What are some general examples of the kind of health information you might look for on the Internet? *[List on chart paper]*

5. Now we will talk about the information that your doctors and other health care providers keep about your health. What kinds of information do they put in an office record when you visit, perhaps writing it in a folder or chart? *[List]*

6. You may have seen doctors looking at or entering this information on a computer during your visit. That's called an electronic health or medical record. It's a record of all your health information, including the information we just listed. The electronic record has notes about your blood pressure, weight and other vitals, your health history, diagnoses, conditions, progress, prescriptions, lab results, etc. Doctors use these computer records to keep track of your health and to manage your care. They can also share your information with other providers electronically.

    a. How many of you were aware that more doctors, clinics and hospitals are using computers to keep and share your health records? [Show of hands]
    b. Do any of your health care providers use computers this way?

7. What do you think of the idea of your doctors keeping records electronically? Are you comfortable with that? (Say, on a scale of 1 to 5, with 1 being "it's a great idea" and 5 being "it's a terrible idea?") [*Collect comments from discussion re benefits and concerns*]

    And what about your health care providers sharing your information? For example, with other doctors or with a lab? (Again say, 1 to 5 with 1 being "great" and 5, "terrible") [*Collect comments from discussion re benefits and concerns*]

*[If someone brings up concerns about privacy or the need for security, acknowledge and say we will be talking about those very things next, and do not begin a general discussion of privacy/security until after #10.]*

8. Have any of you been asked for permission to share your health information through something called a health information exchange – an HIE? An HIE allows your doctors and other health care providers to share your health information electronically so they can coordinate your care and access your health records faster. Timely ability to see your health records can be critical in an emergency situation.

    a. If anyone says yes to a, "for those of you who said yes, did you feel you had enough information to comfortably make a decision about sharing your health information?

b. Is anyone familiar with – or has anyone heard about – CRISP? The Chesapeake Regional Information System for our Patients is an organization that has been awarded the state-wide contract for HIE. There are and will be other HIEs, but CRISP will be the service that makes sure all HIEs can share information throughout the state with all providers and all HIEs.

**Part II: Access and Control (Questions 9 – 13)**

9. Are you able to go online yourself to see your health information electronically? That includes information in your doctors' and hospitals electronic records, if they have them.

   If you cannot do that now, would you like to be able to do it?

10. Some of you have mentioned security and privacy. *Security* consists of the technical and physical ways of ensuring health information is sent and received to only the right people. *Privacy* means that information is protected and it is not seen, used, shared or changed by anyone that is not authorized to do so.

    How concerned are you that information being stored, sent and received electronically is secure so that only people authorized to use the information can see it? [Moderator should go around the group to collect answers.]

11. We will talk some more about possible security measures that protect your privacy.

    For purposes of security (making sure the right person gets the message) would you be willing to have to prove your identity to be able to see your information on a computer? For example, if your doctor's office or a health information exchange needs to be sure you are the person you say you are, would you be comfortable with:

    Being asked for your driver's license or passport in the doctor's office when you ask to start viewing your health records on-line?

    Having your log-on information, with a PIN, mailed to your house?

    Going to your plan or a state organization to sign up for a service that lets you get electronic access to your info?

    Giving additional personal information online to verify your identity?

12. Who do you think should decide which people or organizations will have permission to see your health information? *[Probe]*

13. Who should be responsible for managing the health information that will be shared? Managing includes, for example, deciding what information is part of the shared record and when to remove something from the records. *[Probe]*

**Part III: Education and Outreach (Questions 14 – 18)**

14. From time to time things change because of technology or a change in the health care system.

What do you think would be the best way for you or your family and friends to learn about the changes? For example, changes in how health information is kept and stored, or learning about how you can control how the information is used?

What are the three most important things you would need to know to make you feel comfortable making your decision about whether to allow electronic sharing of your health information?

15. If you need help with new technology, where do you think you will get it? If you do not have a way of connecting to the Internet today, is there an organization where you would comfortably go to ask for help? [*Ask the follow-up question only if the group fails to mention CBOs.*]

    Do you have community organizations now that help you find out about health issues or that help you better understand information you have been given? *[Probe]*

16. Earlier we discussed who you currently trust to provide important health information. Now that we have discussed the changes that are underway with electronic health information, which of these organizations do you trust most to give you information about how your health information is used or shared? [Show them the old list refined during Question number 2, and the list below with other types of community-based organizations]

17. What are the best ways for you and your family to get the information you need about these new changes, such as about electronic health information and your rights in choosing to share your own health information? Pretend you are talking to the people who are responsible for getting you that information; what should they do to get it to you when and where you want it?

[*Probe for regular mail, at the doctor's office, online, with a video, through the organizations we just discussed*]

18. Is there anything else you would like us to know about how you think we should prepare for more electronic sharing of health information?

That is it! We are finished. You have been a great group and the information you have provided today will be very helpful. Please take a moment to complete this survey. When you are finished, just hand in your survey and pick up your gift card before you go.

Thank you very much!

## Appendix E: Consumer Focus Group Survey

Directions: Check one answer for each question. Thank you.

**Please tell us about you:**

1. You are:

   - ☐ Female
   - ☐ Male

2. Your age group is:

   - ☐ 18 to 24
   - ☐ 25 to 34
   - ☐ 35 to 44
   - ☐ 45 to 54
   - ☐ 55 to 64
   - ☐ 65 to 74
   - ☐ 75+

3. The last grade level of school you completed was:

   - ☐ 8th grade or lower
   - ☐ Some high school
   - ☐ High school diploma or GED
   - ☐ Some college or 2-year degree
   - ☐ 4-year college degree
   - ☐ More than 4-year college degree

4. Your yearly household income is:

   - ☐ Less than $22,000 a year
   - ☐ Between $22,000 and $66,000 a year
   - ☐ More than $66,000 a year

5. You are:

   - ☐ American Indian or Alaskan Native
   - ☐ Asian
   - ☐ Black or African American
   - ☐ Native Hawaiian or Other Pacific Islander
   - ☐ White or Caucasian

6. You are:

   - ☐ Hispanic or Latino
   - ☐ Not Hispanic or Latino

**Please tell us about your health care:**

7. In the past two years, how many different visits did you have with health care providers – for example doctors, hospitals, laboratories, clinics, nurse practitioners and dieticians?

☐ 0
☐ 1 – 3
☐ 4 – 6
☐ 7 or more times

8. In the past two years, how many different health care providers, in different offices or departments, have you visited –for example doctors, hospitals, laboratories, clinics, nurse practitioners or dieticians?

☐ 0
☐ 1 – 3
☐ 4 – 6
☐ 7 or more

9. Are you responsible for the health care of someone else, such as an older person or a child under 18 years old? (Including taking them to appointments, helping with medications, etc.)

☐ Yes
☐ No

10. Do you or someone in your family have a long-term health condition such as diabetes, heart disease, or high blood pressure?

☐ Yes
☐ No

11. Do you have health insurance?

☐ Yes
☐ No

**Please tell us about your cell phone and Internet use:**

12. Do you use a cell phone daily or almost every day?

☐ Yes
☐ No

13. Do you use the Internet daily or almost every day?

☐ Yes
☐ No

14. Do you ever look for health information on the Internet?

☐ Yes
☐ No

***Thank you for completing the survey!***

MARYLAND
HEALTH CARE
COMMISSION

# David Sharp, Ph.D., Director

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