

eHealth Board Consumer Interests Workgroup

Assumptions underlying draft recommendations:

- “Consumers:” individuals receiving care or helping to provide, manage, or monitor the care of a family member or others.
- Other eHealth workgroups will identify appropriate technology and financial means to implement these recommendations.

Charge	Status	Discussion Date (proposed)
1. Understand consumer expectations regarding electronic health data exchange (1).	<p>The stakeholder survey had little consumer representation (n=11 self-identified as “consumers”) so the group looked to national surveys.</p> <p>Key resources and findings:</p> <p>Markle Foundation—<i>Attitudes of Americans Regarding Personal Health Records and Nationwide Electronic Health Information Exchange: Key Findings from Two Surveys of Americans</i> (10/05)</p> <ul style="list-style-type: none"> ▪ Americans believe an electronic exchange of health information would enhance quality and increase efficiency of the health care system. ▪ Survey respondents rate attributes of a proposed nationwide health information exchange that focus on security and privacy as the highest priorities. These attributes are also rated as the top reasons for supporting the creation of an exchange or network. ▪ A majority of Americans believe that doctors keeping electronic medical records of their patients would: <ul style="list-style-type: none"> ○ Allow physicians to access medical information at a moment’s notice (93% Agree) ○ Allow physicians to determine what treatments work best for different diseases (81% Agree) ○ Improve health care quality (80% Agree) ○ Be secure and private (66% Agree) ○ Decrease health care costs (60% Agree) <p><i>National Consumer Health Privacy Survey 2005</i></p> <ul style="list-style-type: none"> ▪ Two in three Americans are concerned about the confidentiality 	<p>September 12: Consumer Listening Session</p> <p>September 20 mtg</p>

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	<p>of their personal health information and are largely unaware of their privacy rights.</p> <ul style="list-style-type: none"> ▪ One in eight patients reportedly engages in behavior to protect personal privacy, presenting a potential risk to their health. ▪ More than half (52 percent) of respondents are concerned that employers may use health information to limit job opportunities. ▪ Consumers report a favorable view of new health technology, with a majority (59 percent) willing to share personal health information when it could result in better medical treatment. <p>Next Steps: Consumer Listening Session scheduled for Sept. 12 in Oconomowoc, WI from 1:00 – 4:00. Key themes will be included in action plan.</p>	
<p>2. Identify HIE and HIT outcomes that are highest priority from the consumer perspective</p>	<p>Rec 2.1: Priority consumer outcomes of HIE and HIT:</p> <ul style="list-style-type: none"> ▪ Information exchange that improves patient care ▪ Appropriate consumer and provider access to health information ▪ Security of health information ▪ Improved communication among parties relevant to patient care ▪ Decision support that ensures appropriate care <p>Rec 2.2: Add ‘medical devices’ to high priority EHR/HIE data elements identified by patient care group.</p> <p>Rec 2.3: Highlight the following data elements in patient care list as elements of added privacy concern:</p> <ul style="list-style-type: none"> ▪ Identity/demographics/Master person index ▪ Diagnoses ▪ Medications ▪ Allergies ▪ Labs and Other Diagnostics ▪ Procedures ▪ Patient visits and hospitalizations ▪ Discharge summaries and progress notes 	<p>June 23 meeting</p>

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	<ul style="list-style-type: none"> ▪ Payer/Insurance/Coverage and eligibility <p>Next steps: Patient care WG will address priority areas outlined above in use cases. Consumer Interests WG will review use cases (see charge #7 below).</p>	
<p>3. Define acceptable and unacceptable data use policies to maintain privacy and security including agreements for patient consent and use of data, including:</p> <ul style="list-style-type: none"> ▪ Whether patients will be permitted to opt-out of having their information in the exchange ▪ How patients will access their own data 	<p>Rec 3.1: In accordance with current Wisconsin law (providers <i>shall</i> share patient information for treatment purposes) patients will not be permitted to opt-out of including their general health information in Wisconsin’s information exchange.</p> <p>Recommendations regarding the possibility of opting out of including more sensitive information are in progress (see charge #4 below).</p> <p>Rec 3.2: Adopt Markle Foundation <i>Consumer and Patient Principles for System Design</i> as a template for recommendations related to access.</p> <ul style="list-style-type: none"> ▪ Individuals should be able to access their health and medical data conveniently and affordably (#1) ▪ Individuals should be able to decide (i.e., authorize) when their health data are shared, and with whom (#2) ▪ 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 (#3) ▪ Individuals should receive easily understood information about all the ways that their health data may be used or shared (#4) ▪ Individuals should be able to review which entities have had access to their personal health data (#5) ▪ Electronic health data exchanges must protect the integrity, security, privacy, and confidentiality of an individual's 	July 28 meeting

Charge	Status	Discussion Date (proposed)
	information (#6)	
<p>4. Make recommendations on whether health information with special protections will be included in electronic health data exchange, such as information about:</p> <ul style="list-style-type: none"> ▪ Mental health ▪ Alcohol and drug abuse treatment ▪ Communicable diseases ▪ Genetic testing <p>And potential limits required on the use and disclosure of that special information (5b).</p>	<p>Rec 4.1: Add the following areas to discussion of sensitive health information:</p> <ul style="list-style-type: none"> ▪ Adoption ▪ Developmental disabilities ▪ Sexual assault ▪ Domestic violence <p>Rec 4.2: Discussions should differentiate between areas delineated by HIPAA (treatment, health care operations, payment, public health).</p> <p>Rec 4.3: Current controlling law (Wisconsin law or HIPAA) should serve as the foundation for treatment of sensitive information (i.e., whether or not patients can opt-out or opt-in).</p> <p>Rec 4.4: Patients should be made aware of the risks and benefits of excluding their health information from exchange.</p> <p>Key concerns identified in discussions to date:</p> <ul style="list-style-type: none"> ▪ What is included in exchange ▪ Who has access to the information exchanged ▪ A patient/consumer’s ability to influence (or limit) access ▪ Whether an individual is receiving routine or emergency care <p>Next steps: Compile current practices under controlling law for each type of sensitive information. Workgroup members, resources, and Sept. 12 attendees (?) will be asked to weigh in with concerns or suggested policy changes in each area.</p>	<p>July 12 meeting, Continued: July 28 Aug. 21</p>
<p>5. Define acceptable and unacceptable data use policies for oversight purposes, including (5a):</p> <ul style="list-style-type: none"> ▪ Public health ▪ Research 		<p>July 28 meeting Cont: Aug. 21</p>

Charge	Status	Discussion Date (proposed)
FIRST UPDATE to eHEALTH BOARD: AUGUST 3		
6. Identify desired outcomes and options to meet consumer expectations regarding electronic health data exchange so that consumers are well prepared to manage their own health care and to advocate for themselves as they use health care services and to support mutual accountability for health. (1).	Discussion topics: <ul style="list-style-type: none"> ▪ Education campaign (including PHR) ▪ Possible encouragement of patient-provider e-communication 	August 21 meeting
7. Define recommended guidelines and real-world examples that clarify how data sharing can balance the requirement to protect patient privacy and system security with the need to share information to improve patient-centered care (3).	Discussion topics: <ul style="list-style-type: none"> ▪ Patient care workgroup chair or staff present use cases ▪ Workgroup discuss use cases as a double-check for: <ul style="list-style-type: none"> ○ Appropriateness of recommendations to date ○ Meeting consumer health-information needs 	August 21 meeting
8. Identify specific legal actions required for the priorities recommended by the clinical work team, including (5c): <ul style="list-style-type: none"> ▪ Whether statutory/regulatory amendments are needed ▪ Practical, non-technical strategies and solutions for developing electronic health data exchange that will ensure the secure and confidential transmission of personal and medical information. 		Sept. 20 meeting Oct. 3 meeting
9. Review draft and adjust recommendations		October 3 meeting

Charge	Status	Discussion Date (proposed)
REVIEW FIRST (FULL) DRAFT OF eHEALTH ACTION PLAN (VIA EMAIL OCT. 9-24)		
10. Finalize recommendations	Topics for discussion: <ul style="list-style-type: none"> ▪ Governance <ul style="list-style-type: none"> ○ Tentatively adopted <i>Markle Consumer Principle</i> stating: 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. ▪ Financing <ul style="list-style-type: none"> ○ revisit after reviewing finance workgroup recs. ▪ Review draft recommendations to date 	October 23 meeting November 6 meeting
REVIEW SECOND (FULL) DRAFT OF eHEALTH ACTION PLAN (VIA EMAIL NOV. 7-10)		
11. Submit final draft to eHealth Board		November 14
12. Final Action Plan submitted to Governor		December 1

Issues for discussion with eHealth Board:

- (1) To what extent should the Consumer Interests workgroup be thinking about possible changes to Wisconsin law? To what extent should existing law be considered as a guide?
- (2) Thoughts about the scope of the Consumer Interests workgroup's activities? Other areas the workgroup should address?
- (3) Comments about the September 12 Consumer Interests Listening session?