Consumer Empowerment
Background and Options Paper
Breakthrough Models

Office of the National Coordinator for Health Information Technology

February 21, 2006

The following information has been provided to you by the Office of the National Coordinator and is a synthesis of data collected from collaboration with the co-chairs, expert members of the community, and other workgroup members. This information is for your careful review and should be factored into the decision-making process at the February 21, 2006 Consumer Empowerment workgroup meeting. The meeting should focus on deciding upon recommendations that must be made to the Secretary and the American Health Information Community at the March 7, 2006 meeting.
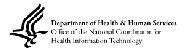
Charges for the Consumer Empowerment Workgroup

- **Broad Charge for the Workgroup:** Make recommendations to the Community to gain wide spread adoption of a personal health record that is easy-to-use, portable, longitudinal, affordable, and consumer-centered.
- **Specific Charge for the Workgroup:** Make recommendations to the Community so that within one year, a pre-populated, consumer-directed and secure electronic registration summary is available to targeted populations. Make additional recommendations to the Community so that within one year, a widely available pre-populated medication history linked to the registration summary is deployed.

There are a variety of ways data can be provided to consumers and their providers. The options presented in this paper represent the most immediate options available, however; the workgroup should not feel compelled to select one of the options. The workgroup can consider which models are appropriate following the critical criteria listed below.

Critical criteria in development of specific charge recommendations:
- Feasible to implement in 2006.
- Accomplishes the specific charge, while facilitating the most direct path to the broad charge of widespread PHR adoption.
- Illuminates the significant barrier(s) that must be resolved to achieve breakthrough success (policy and technical).
- Delivers the value to the consumer over the next 1-2 years.

- Leverages all stakeholders, while appropriately balancing expectations, responsibilities and authority.
- Aligned with other breakthrough activities.

Options for PHR Models

Option 1: Use an existing regional health information exchange with a consumer interface.

In this model, a regional health information exchange is currently providing clinical information at the point of care for the treatment of patients. The clinical information provided includes registration summary and medication history, however; other data such as radiology reports, and pathology reports could also be made available. A consumer interface to the health information exchange is built and consists of a subset of clinical information. .

Pros
- A very strong advantage is the use of an existing and functioning infrastructure to provide health information. This obviates the need to build the network, arrange for clinical information sources, establish most communication links, choose data structures, and select a patient identification methodology
- Because providers are already taking care of patients by using electronic health information exchange to obtain needed clinical information at the point of care, consumers are already comfortable with and have confidence in electronic exchange of health data.
- A broad variety of clinical data in addition to registration and medication information can be made available to the consumer and stored in the PHR.
- This option is feasible in 2006 in more than one existing regional health information organization.

Cons
- Given that the current system is used by providers through institutional systems with sophisticated security features, the addition of a consumer interface might increase the actual or perceived risk of compromises to the security of the network.

Option 2: Expanded version of Katrinahealth.org with registration summary linked to med history.

KatrinaHealth.org is a secure, online service established within a month after Hurricane Katrina that gives authorized healthcare providers access to medication and

dosage information for evacuees from Hurricane Katrina. The information in Katrina.Org was compiled by a group of organizations, including medical software companies, pharmacy benefit managers, chain pharmacies, and local, state, and federal agencies. The site allows authorized physicians and pharmacies to view prescription information for an evacuee such as quantity and day supply, pharmacy that filled the prescription and provider who wrote the prescription, however medication information is excluded for sensitive health conditions such as mental illness, chemical dependencies or HIV/AIDS. Authorized users access patient prescription information by entering the evacuee's first name, last name, date of birth, pre-Katrina residence zip code and gender.

Pros
- The organizations that built Katrina.Org have already worked together and could more quickly and easily work on an expanded version of the system than organizations that are not knowledgeable of Katrina.Org.

Cons
- KatrinaHealth.Org had a limited impact (i.e., only a few thousand successful inquiries) and was not easy to integrate into clinical workflows.
- The system would need to be expanded and modified to include registration information for patients.
- KatrinaHealth.org provides "Read Only" access and information in the system cannot be modified or otherwise changed by the treating health professional. The system would need to be redesigned to allow updates and additions to existing medication information.
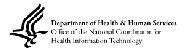
Option 3: PHR vendor(s) linked to one or more intermediaries to get updated registration and medication information.

In this model, PHR vendors would send and receive consumer registration and medication information that resides in intermediary data repositories. The intermediaries interface with a variety of "source" systems, such as PBMs to obtain patient medication information.

Pros
- Easy for consumer PHRs to be automatically populated and updated with valid information from source systems.
- Minimizes modifications to source systems because they would not need to be tailored to communicate with a variety of PHR products, but rather to communicate with only one system—the intermediary's data repository.

Cons

- Consumers might have privacy and security concerns about their registration and medication data being held by an intermediary or in a central data repository.
- PHR vendors are not recognized as business associates under HIPAA.

Option 4: Payer or employer portal linked to PHR vendor(s)

In this model, consumers would use a portal provided by a health care payer (i.e., their employer or health insurer) to connect to their PHR, which is provided by a PHR vendor.

Pros
- The PHR could be automatically populated and updated with prescription information contained in a payer system.
- The PHR could be automatically populated and updated with health insurance benefits ("registration") information contained in a payer system.
- The Medicare program and private health plans are both rolling out portals and PHR-like services.

Cons
- Consumers might not trust a payer or employer with providing or maintaining their personal health information. It might be perceived as a way to justify higher premiums or result in a loss of insurance or employment.
- The medication information in the payer system would be limited to those prescriptions for which an insurance claim was submitted. Consumers might not submit claims for prescriptions for sensitive health conditions such as mental health.
- Pre-populated claims data has questionable quality and might contain inaccurate information.