

Consumer Empowerment Briefing Document

Office of the National Coordinator for Health Information Technology

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In the following paragraphs and pages you will find the broad and specific charges to this workgroup, some definitions to assure consistent communications, and some background information. We have also included some questions that may be useful starting points for your discussion and ask that, working with ONC, you endorse final highly specified recommendations regarding what is to be accomplished by year's end, the specific populations which will derive benefit, and the critical actions that must be taken for successful implementation. Your presentation of these recommendations at the March 7th Community meeting will shape the intent of the Community in this area.

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.

Who is involved in realizing these charges?

- **Healthcare Consumer/Patient** - The individual who receives healthcare services and selects a vendor or provider to collate and maintain their personal health information which, in the case of the specific charge, consists of registration data and medication history. This individual shall determine which stakeholders are authorized to review these components of a personal health record.
- **Authorized Family Member/Caregiver** - A person or person(s) who have authority to act on a consumer's behalf regarding actions taken with these components of a personal health record.
- **Clinicians/Provider/Medical Institutions** - The person or entity providing medical care to the consumer.
- **Ancillary Service Providers** - The organization or entity providing ancillary services to the consumer such as laboratory services.
- **Pharmacies** - The organizations that dispense pharmaceuticals to consumers, utilize personal health data to check for possible contraindications; could

- participate in the population of these elements of a personal health record, and could act as the provider of the registration and medication records.
- **Payers** - The organization that pays for healthcare claims, can participate in the population of the registration and claimed medications record, and can act as the provider of personal health record products.
 - **Pharmacy Benefit Managers** - The organizations that have delegated authority from the payer to process pharmaceutical claims, can participate in the population of and can act as the provider of the registration and medications record.
 - **Public Health Agencies (Federal, State, Local)** - Federal, state, local organizations and personnel that exist to help protect and improve the health of their respective constituents. **Employers** - The organizations that employ the consumer, provide insurance coverage for pharmaceuticals, and can act as the provider of the registration and medication records.
 - **Emergency Clinicians** - Healthcare providers providing urgent medical care to consumers who may or may not require consumer authorization for accessing personal health record information.
 - **Schools** - The organizations that may act as the provider of PHR information for its student population.
 - **PHR provider**- The entity or organization that possesses and possibly aggregates registration data and the medication history, as well as other personal health information, for the consumer in a secure environment.
 - **Regional Network Infrastructure** - A local or region-specific computer systems network responsible for transmitting data among authorized or certified entities.
 - **EHR Systems** - The electronic health record is the legal medical record maintained by healthcare providers.
 - **Provider Administrative Staff** - The employees and contractors who work for the healthcare provider.
 - **Administrator of Healthcare Delivery Organization** - The director, chairperson, or authoritative body leading the administration of the organization.
 - **Data Mappers (functional and technical)** - The organization that normalizes and links medical vocabularies to a common identifier or reference for use in reporting and documentation in a personal health record.
 - **System implementation and maintenance POCs** - The applications used in supporting or maintaining the personal health record data.
 - **Sub-Network Organizations** - An entity supplying the infrastructure to link consumer health data between organizations.
 - **Data Consolidators** - A software application engine that can aggregate the consumer's medication records gathered from multiple data suppliers participating in the SNO.

What is already being done?

Medication history:

- KatrinaHealth.org is a secure online service to help individuals affected by Hurricane Katrina work with their health professionals to gain access to their own electronic prescription medication records. Authorized pharmacists and doctors can get records of medications evacuees were using before the storm hit, including the specific dosages. The information provided on this website is meant to complement, not substitute for, complete information provided to the doctor or pharmacist by his or her patient or client.
- To protect patients' privacy, medication information about medications for HIV/AIDS, mental health issues, and substance abuse or chemical dependencies is not available through KatrinaHealth.org. In addition, the American Medical Association (AMA) is providing physician credentialing and authentication services and will validate the identity of health care providers. The National Community Pharmacists Association (NCPA) and SureScripts are providing authentication and access for independent and chain pharmacies. Tools are in place to prevent unauthorized access, and audit logs of who has access to the system and what records are being accessed will be rigorously maintained and reviewed..
- The information on KatrinaHealth.org has been made available from more than 150 private and public organizations' electronic databases from commercial pharmacies, government health insurance programs such as Medicaid, private insurers, and pharmacy benefits managers in the states affected by the storm. Key data and resources were contributed by the American Medical Association (AMA), Gold Standard, the Markle Foundation, RxHub and SureScripts. Data contributors also include: the Medicaid programs of Louisiana and Mississippi, chain pharmacies (Albertsons, CVS, Kmart, Rite Aid, Target, Walgreens, Wal-Mart, Winn Dixie) and Pharmacy Benefit Managers (RxHub).

Registration Summary:

- Similar to the operating rules that govern interoperability for ATM and credit card transactions, CAQH is facilitating a multi-stakeholder initiative to develop business rules that will govern the exchange of information as it relates to eligibility and benefits. With the rules, the industry will have a standard process and content for eligibility and benefits interactions between healthcare providers and payers, including response time, exception processing and error management. CMS is supporting the CAQH effort to develop agreed-upon operating rules to guide the way eligibility and benefits information is exchanged.

- Access to reliable eligibility and benefits information at the point of care will reduce the amount of time providers spend on administration by improving the accuracy of claims submitted and providing enhanced information on patient financial responsibility. The HIPAA Transaction Rule and standards provide a foundation for the exchange of eligibility and benefits information, but does not go far enough to promote the interoperability needed. The data scope identified by HIPAA is limited, and elements needed by providers are not mandated. Further, HIPAA neither standardizes data definitions nor offers business requirements (e.g., timely response).
- The rules will build upon the HIPAA 270/271 transactions for eligibility and benefits and address the following information:
 - Which health plan covers the patient
 - Confirmation of service type
 - Confirmation of patient's co-pay amount
 - Confirmation of patient's coinsurance levels
 - Confirmation of patient's base deductible levels

Related Federal Efforts/Resources:

- Although CMS, VA, DoD, and OPM have access to various types of health care information, each operates under different legislative authorities and regulatory schemas. The DoD uses clinical data, encounter data, claims data (from external providers), and information on eligibility whereas OPM has only eligibility and benefit information available. CMS has both eligibility/benefit data and claims, but no access to patient specific clinical information. The VA, like other federal providers of care, has full information sets on patients treated within its system, but not from providers outside the VA.
- Currently the VA and the DoD have both launched unique and non-coordinated personal health information tools, with variable linkages to other services. CMS has a beneficiary portal pilot project planned for nationwide rollout in 2006 which will provide eligibility, benefit, and claims information, but no linkage to medication renewals, appointment scheduling, email, etc. At present, each federal agency has its own system of identifying patients or beneficiaries.

Modeling the project

1. What are the minimum data elements of a registration summary?
2. What are the data sources for these data elements?
3. What is the scope of the medications listed, bearing in mind sensitive information protected by state specific law?
4. What are the data sources for medication lists?

5. What is the best approach to consumer control and management of data while maintaining data validity: limit to specific fields? Flag fields that patient may have modified?

Defining the populations

1. What is the best way to address the uninsured, the underserved, and safety net providers? Should we consider state based or regional options?
2. Given that provider workflows are consistent across all patients, are there specific patient populations that should be encouraged to utilize this product, and how?

Other

1. How should we limit liability risks?
2. What will encourage providers to adopt use of this information into their workflow?
3. How do we encourage the market to participate and/or develop?
4. How do we address state specific privacy and security issues?