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Consumer Empowerment
Registration Summary and Medication History
Data Elements and Data Sources - Background and Options Briefing

For Discussion at the
Consumer Empowerment Work Group Meeting
February 21, 2006
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Reminder of Consumer Empowerment Work Group Charges

- **Broad Charge:** 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:** 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.

Objective for the February 21, 2006 Meeting

Discussion will focus on data elements and data sources only, with the Broad and Specific Charges as context. Review the data elements and data sources options and decide on the recommendations that must be made to the Secretary and the American Health Information Community at their March 7, 2006 meeting.

Background

Identifying both the data elements and the data sources for a pre-populated registration summary and medication history is a necessary first step in achieving the Specific Charge for the Work Group. In identifying the data elements and their data sources, the following questions must be considered:

1. What are the minimum data elements of a registration summary and a medication history?
2. What are the data sources for these data elements?
3. What are the clinical, business, and consumer needs that drive the requirements for including certain data elements in the registration summary and medication history?
4. What is the best approach for consumers to control and manage their health information while maintaining data quality and validity?

In going through this process, it is important to remember that consumer privacy is the most important principle for guiding:

- The selection of the data elements and data sources for the registration summary and medication history.
- The process in which such health information is collected and exchanged between consumers, providers, payers, pharmacies, and all other participants.

Once data elements and their respective data sources for the registration summary and medication history have been decided upon, the options to implement them are influenced by the following critical criteria listed below.

Critical criteria in development of specific charge recommendations:
1. Feasible to implement in 2006.
2. Accomplishes the specific charge, while facilitating the most direct path to the broad charge of widespread PHR adoption.
3. Illuminates the significant barrier(s) that must be resolved to achieve breakthrough success (policy and technical).
4. Delivers the value to the consumer over the next 1-2 years.
5. Leverages all stakeholders, while appropriately balancing expectations, responsibilities and authority.
6. Aligned with other breakthrough activities.

Data Elements and Their Data Sources: Key Points

The data elements and their potential data sources are listed in Appendix A. The data elements list (Column A) is a synthesis of those contributed by all stakeholders to date.

- The list of data elements is lengthy. Implementing all the data elements in the list in one year may not be feasible or possible.
- The data elements are broken down by a suggested Minimum Data Set (Col. B) and an Optional Data Set (Col. C). Data elements can be flexibly assigned to the minimum and optional data sets. The data set approach enables all agreed upon data elements to be implemented in phases, if necessary.
- Since this is an open and transparent process, data elements not agreed upon should be identified (Col. D), informing the public that certain data elements have been considered, but are not thought to be necessary for the registration summary or medication history.
- The registration process is an <u>event</u>. The work group should decide whether the data elements for the registration summary and medication history should be constrained just to support that event, or if data elements should be included to support downstream events. The latter will result in a greater number of data elements to be exchanged at registration.

The data sources for a number of key stakeholders are identified in the table as well (Cols. E – J).

Where there are multiple data sources, the data element should be retrieved from the source that:
- Is indicated in that step of the work flow. However, the work flow should be <u>optimized</u>, capitalizing on the efficiencies of technology.
- Contains the highest data quality and validity.

Example Scenario: Checking Insurance Benefits at First Visit, with a PHR

- Consumer presents at physician's office. Since demographic information can be maintained well by the consumer, that information can be exchanged between the PHR and the provider's EHR.
- The PHR contains insurance data elements such as insurer, the plan, group number, and ID number, but not (necessarily) data elements on the plan's coverage and benefits. Storing plan coverage and benefits in the PHR may increase the consumer's responsibility for maintaining this information for which he/she may be less well equipped or willing to do so, as well as the storage requirements for the PHR.
- The payer maintains plan coverage and benefits. The payer is better equipped and motivated to accurately maintain plan coverage and benefits.

- When the PHR discloses the insurance information to the provider's EHR, the provider's EHR can access the insurer's web site, confirm that the consumer is still covered by the plan, and retrieve the covered benefits under the plan.
- The PHR is not a legal record. Downloaded clinical health information from a provider's EHR (a legal record) and claims information from a payer's website must be stored in a "protected" (read only) region of the PHR so that the consumer cannot inadvertently modify such data. The transaction above between the provider's EHR and the payer's website will ensure that more accurate information is exchanged.

Options for Data Elements and Data Sources

Option 1: Implement minimum data sets for registration summary and medications history (after determining the data elements to be included in the m) for a limited set of stakeholders (e.g., subpopulations of consumers, providers, payers, and pharmacy benefit managers) in Year 1. Include other stakeholders and implement optional data sets after Year 1.

Pros: Tightly Scoped, Ensures Higher Success Rate
- Defining standard data definitions, data sources and health information exchange standards for fewer data elements will ensure higher data quality and validity
- Gives more focused direction and time to stakeholders who must develop software and websites to support this option
- Lower cost to implement initially
- Faster implementation, necessary given aggressive time frames under the work group charges
- Success may be more immediately visible to consumers, providers, and payer increasing stakeholder support

Cons: Deferring Other Important Clinical, Business, or Consumer Needs
- Other important clinical, business, or consumer needs will be deferred until after the Year 1
- If the project's initiative is not sustained, these needs may not be addressed
- Potentially higher cost than if done all at once. Need to determine marginal cost for including optional data elements when working on the minimum data set.
- Stakeholders may not be entirely satisfied because the full set of clinical, business, or consumer needs for the "clipboard" aren't addressed

Option 2: Implement minimum and optional data sets for registration summary and medications history all at once for a limited set of stakeholders in Year 1. Include other stakeholders after Year 1.

Pros: Satisfies Consumer, Clinical, And Business Needs Sooner
- Important clinical, business, or consumer needs will not be deferred
- Can address other consumer empowerment needs beyond registration summary and medication history more quickly
- May be lower in cost if all done at once rather than in phases. Need to determine marginal cost for including optional data elements when working on the minimum data set.
- Stakeholders may be more satisfied because the full set of clinical, business, or consumer needs for the "clipboard" have been addressed

Cons: Deferring Other Important Clinical, Business, or Consumer Needs
- Defining standard data definitions, data sources and health information exchange standards for a larger set of data elements will take longer to develop
- Longer implementation time frames, may put Year 1 goals at risk