Department of Health & Human Services
Office of the National Coordinator for Health Information Technology

Consumer Empowerment
Background and Options Briefing
Target Populations and Geographic Scope

Office of the National Coordinator for Health Information Technology

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The following information 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 review and should be factored into the decision-making process at the February 21, 2006 Consumer Empowerment workgroup meeting. The meeting will 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.

Options for potential patient populations and geographic areas for the specific charge are listed below and represent the input received to date. This is not intended to be an exhaustive list of options that represent all short-term possibilities for defining the breakthrough. Please use the following criteria as you review and consider these options for the breakthrough.

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 Target Populations

Option 1: Pediatric patients

- *Pros*
  - Young healthy parents have the incentive and motivation to create and maintain their childrens' PHRs
  - Younger generations are more computer savvy and willing to participate
  - Studies show that pediatric patients with asthma who have PHRs, have better health outcomes and less visits to the ED and hospital
  - A pilot could be feasible in 2006 if leveraged through an AHRQ contract with the state of Colorado for establishing health information exchange for pediatric care
- *Cons*
  - The breakthrough project will initially only benefit pediatric patients taking medications or pediatric patients and their parents who visit pediatricians often (convenience of electronic clipboard)
  - Adolescents (12-18 years old) typically do not have access to PHRs because they are too young to sign a release of information
  - State laws prohibit parental access to certain types of health information

Option 2: Patients with chronic diseases

- *Pros*
  - Patients with chronic disease have a medical necessity to document their care and are typically on multiple medications
  - A PHR with medication history could also enable communication with their clinicians regarding their medication management
  - Patients tend to visit physicians more frequently than healthier populations and would likely find an "electronic clip board" convenient
- *Cons*
  - Clinical benefits of improved medication management (in terms of efficacy) through the availability of medication history might take longer to demonstrate in a population with chronic disease
  - Patients with chronic diseases often need more information than medication lists

Option 3: State Medicaid or Medicare beneficiaries

- *Pros*
  - CMS beneficiary portal could enable a demonstration in 2006
  - Patients are commonly on multiple medications and their providers would benefit from having access to their complete medication history
  - Eligibility and benefit information could be readily available to clinicians and avoid delays
  - New Medicare beneficiaries could receive PHRs as part of the "welcome to Medicare" physical
- *Cons*
  - Many State Medicaid programs might not have the resources to administer a breakthrough program

Option 4: Uninsured population

- *Pros*
  - Could allow emergency room physicians access to medication history to facilitate appropriate treatment for those who access care in ED
  - Could work with federally funded community health center population through CHC network grants
- *Cons*
  - Demographic data and medication history might be difficult to obtain
  - Uninsured poor may not have access to computers or the Internet

Option 5: Caregivers for the elderly population

- *Pros*
  - Could demonstrate value to caregivers (or family members) in the short term for elderly in long term care facilities
- *Cons*
  - This is probably more relevant to the broader charge

Options for Geographic Scope

Option 1: States with the infrastructure and organizational capacity

- *Pros*
  - Elucidate the breakthroughs (including policy and governance) necessary for other states that do not have the necessary infrastructure or organizational capacity
  - Builds on existing infrastructure and allows evaluation of benefits

- Helps set vision and role for the state as breakthrough implementation is expanded
- AHRQ has 6 contracts for state level health information exchange which could be leveraged for the breakthrough
- 30 states have proposed or passed legislation

- *Cons*
  - Early stage of pilot might be more successful in a smaller geographic area prior to launching a state-wide program
  - Some state privacy and security laws might be barriers to implementation

Option 2: Regions with large employers and/or plans offering programs

- *Pros*
  - Opportunity to leverage private sector capital, infrastructure, and expertise
  - Immediate access to populations to distribute PHRs; with employers, it is even more convenient
- *Cons*
  - Does not reach uninsured or underinsured
  - Unless employers or plans represent a large proportion of a patient population, providers might not integrate the information from participating patients into their work flow
  - Privacy concerns with employers may be a barrier

Option 3: Regions with operational Health Information Networks

- *Pros*
  - NHIN prototypes will have demonstrations in 12 local health care markets in 2006 (use case will direct their implementation)
  - Some health information exchanges (HIEs) are already operational and could add the technologies and functions needed for this breakthrough
  - Opportunity to assess value of RHIO
- *Cons*
  - Limited number of functional RHIOs