Consumer Empowerment
Background and Options Briefing
Policy Issues and Barriers

Office of the National Coordinator for Health Information Technology

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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 should be carefully reviewed and 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.

Background Information

The first requirement stated in the AHIC Charter is: "Protection of health information through appropriate privacy and security practices." The specific and broad charges for this breakthrough raise numerous policy questions for which there are no answers available today. In addition, there are several policy issues and barriers identified in the first work group meeting that warrant further consideration. These include:

1. Lack of interoperability. How can we ensure interoperability between PHRs and EHRs? Do PHRs need to be certified to ensure they meet privacy and security, functionality and interoperability requirements?
2. Need for proxies. Can caregivers or family members access a patients record's as authorized?
3. How do we protect personal health information in PHRs?

4. Inaccurate information could lead to medical decisions that result in bad health outcomes. Is this a significant liability issue and if so, how should it be addressed?
5. Lack of consumer awareness. How can we educate and engage consumers and their providers about the benefits of PHRs?
6. Lack of a unique patient identifier. How do we reliably match patients to their health records? (please refer to paper on this subject)

Many of these questions can only be answered in the context of the specific scope of the breakthrough initiative.

A successful policy framework should reflect the deliberate consideration of diverse stakeholders, and consultation with leading technologists. As this is a new area of both technology implementation and public policy, it is essential to develop initial policies and practices and refine them as experience and new questions accrue. The work group process should result in uniform and well-supported policy recommendations. This will guide the work in the public and private sector as the breakthrough project is implemented.

The workgroup should undertake a process to identify and address these and related policy challenges. The process should be based on:

- Well-defined mission or charge
- Policy analysis in the context of the specific scope of the breakthrough
- Strategic input from public interest leadership
- Equal representation of key interest groups, including consumers, patients, providers and payers
- Accountability to affected stakeholders
- Transparent and open process
- Builds upon existing standards and policy work
- Minimizes barriers to entry for health IT solutions
- Minimizes impact on economic performance
- Supports long-term evolution and innovation.