

November 29, 2005

The Honorable Mike Leavitt, Secretary
U. S. Department of Health and Human Services
Chair, American Health Information Community
200 Independence Avenue S.W.
Washington, D. C. 20006

Dear Secretary Leavitt:

Thank you for your leadership of the American Health Information Community and for your support of a seat at the table for the consumer/patient voice. Today, we are submitting for the record the collaborative comments of the organizations from the consumer and patient sector that are actively serving on the consumer/patient working group. The documents include a matrix of the Consumer/Patient Principles of Eight Breakthrough Initiatives in a concrete, summary format that allows for expeditious review of the primary points made in the larger narrative comments provided to us by the members of our working group. Both documents are attached, along with a listing of the consumer organizations. Further insights presented in the matrix have been provided in conference calls with HIMSS, The Markle Foundation, Health Privacy Foundation and personal presentations to the Cancer Leadership Council.

It is important to note that the comments and recommendations in the Matrix are the results of universal collaboration with the groups represented to define universal concerns of these constituencies; however, the comments do not represent universal consensus but rather universal collaborative points of view. In a conference call today, the working group discussed the matrix and updated and expanded it to reflect current thoughts relative to the subject of the AHIC meeting on November 29, 2005.

Please provide a copy of our documents to each of the AHIC contractors so that they too will be informed of the current position of the patient/consumer community as each breakthrough is developed. Moving forward, these documents will be refined and expanded as the needs of the patient/consumer group are brought forward in discussion.

It is a privilege to serve on your Community of appointees to bring the voice of the patient/consumer to the discussion. Our community remains optimistic that the patient/consumer views will be a centerpiece of all recommendations of AHIC in the Breakthrough areas and that inclusion of those views will affirm the public trust in the process used by AHIC to shape future recommendations to Congress. Many of our constituents feel that My Medication Record, My Record Locator, My Registration Info, E-Prescribing and Immunization Records are achievable priorities for AHIC. Additionally, we would offer that these priority areas could be the foundation of the definition of Personal Health Records, thus assuring that PHRs result from the individual work of completing each of the priority items previously identified.

Respectfully submitted on behalf of the Patient/Consumer Working Group Collaborators,

Nancy Davenport-Ennis, CEO
National Patient Advocate Foundation

Cc: Dr. David Brailer, National Coordinator for Health Information Technology

