

September 10, 2007

Secretary Mike Leavitt
C/o Office of the National Coordinator for Health Information Technology
Department of Health and Human Services
Attention: AHIC Successor White Paper Comments
Mary C. Switzer Building
330 C Street, S.W., Room 4080
Washington, DC 20201

RE: American Health Information Community Successor White Paper

Dear Secretary Leavitt,

As organizations committed to fostering improvement in the quality, safety, and efficiency of the American health care system, we are writing to comment on your proposal to create a successor entity to replace the AHIC, as outlined in the AHIC Successor White Paper.

The AHIC was created in 2005 to provide recommendations to HHS on advancing health information technology (HIT) to improve patient safety and public health while protecting the privacy and security of personal health information. This “national collaboration” was expected to accelerate progress toward the President’s goal of implementing electronic health records for most Americans by 2014. While we appreciate your efforts to move forward with nationwide, interoperable HIT, we believe these efforts have been hampered by AHIC’s lack of independence and authority to consider and recommend critical matters of policy *before* an HIT architecture is in place.

Our organizations – which have been actively and constructively engaged in AHIC workgroups and forums since its inception – share the view that AHIC has the potential to play an important role in advancing the nation’s HIT goals, but only if it is strengthened through improvements in its scope of authority, structure and functions. In a July 30 letter to you, we commented on the AHIC 2.0 idea. This letter builds on those comments in the context of the AHIC Successor White Paper.

We believe AHIC in its current form needs to be strengthened, so that it has clear authority and independence to recommend national, uniform policies to ensure the effective implementation of a nationwide, interoperable information network that fully serves the interests of patients and their families. In summary, AHIC should:

- Be independent from both legislative and executive branches;
- Be publicly accountable and transparent;
- Consist of members appointed by a diverse set of agency and congressional leaders and function as a forum for the broadest possible range of public and private-sector health care stakeholders;
- Receive a stable and reliable stream of federal dollars to support its activities, ensure accountability to the public, and protect against conflict-of-interest;

- Ensure meaningful participation from consumer groups;
- Have a clear sense of mission and direction, with appropriate benchmarks for advancing an HIT infrastructure that will improve the delivery of health care in this country;
- Have a clear mandate to make recommendations on such key concerns as the protection of individually identifiable health information, notification of security breaches of individuals' health information, security of health information, patient control over the use of their health information, and the appropriate functions of a nationwide HIT network; and,
- Advise not only the Secretary of HHS, but also Congress and other federal agencies, regarding HIT issues.

Unfortunately, the current proposal to reconstitute AHIC so that it is removed from public oversight and accountability will do little to strengthen it and instead will significantly undermine its long term ability to serve the public. *We urge you to reconsider your current plans and work with Congress to pass legislation that will give AHIC the authority and mission it needs to develop appropriate HIT policy recommendations that reflect the national interest.*

Our specific comments regarding the White Paper are as follows:

AHIC Should be Empowered to Make Policy Recommendations

We believe the AHIC, or any successor entity, should have clear authority and independence to develop and recommend national policies to ensure the effective implementation of a nationwide system of HIT that serves the interests of patients. Unfortunately, the White Paper does not provide a clear vision for the AHIC successor's policymaking role. The "Purpose and Scope" of the successor entity, as outlined in the White Paper, suggest that AHIC would not have a role in making critical recommendations concerning policies to encourage adoption and use of HIT, or to secure the privacy of personal health information. Yet later sections of the White Paper appear to envision just such policymaking. For example, Section D indicates that AHIC will actively identify "legislative or regulatory impediments" to interoperable HIT, and identify the "means and methods to overcome them." Such activities will require a process of policy analysis and decision-making, and AHIC's purpose and scope of authority should reflect this.

Further, while we are pleased to see that the work of the AHIC successor would be guided by a "sound policy framework to ensure confidentiality, privacy, and security," the White Paper is silent on who would develop this framework, on what timeline, or how it would be integrated into the work of the AHIC successor. We believe it is essential that such a framework be in place as rapidly as possible, before moving forward with standard-setting and product certification. In fact, we do not believe standards harmonization, product certification, or priority setting for interoperable HIT can be realistically separated from the entity's policy-making role. Standards are de facto policies, and products cannot be certified in a policy vacuum. We believe that policies relating to interoperability, access, privacy and security can and should drive the technical standards, not the other way around. We urge you to clearly define AHIC's authority and role so that it can proactively and credibly tackle the policy challenges that must be addressed before we can successfully implement nationwide, interoperable HIT.

Organizations Representing Patients and their Families Must Be at the Table

To ensure that an interoperable HIT system fully serves the interests of patients, we urge you to make consumer participation in AHIC a top priority. But the White Paper suggests that AHIC members who want a voice in the running of the AHIC successor and its affairs, including the election of its governing board, would be required to pay dues and make initial capital contributions. This financial requirement could significantly impede the participation of consumer members with limited financial resources, as well as other valuable stakeholders, including providers who care for underserved populations, non profits, and local public health organizations. We believe any initial capital contribution should be waived for such organizations, as well as any dues. At a minimum, there should be a sliding scale for financial contributions based on each organization's level of resources.

Furthermore, while we appreciate the White Paper's provision for multiple options for participation, we urge you to ensure that this structure does not adversely affect the representation and voting rights for consumer members. The White Paper envisions "consumers" as only one class of health care stakeholder, but we believe consumers must have a meaningful and powerful voice in all aspects of AHIC decision-making in order to engender public trust in the process and ensure that actions and recommendations fully serve the interests of patients and their families. This is a concern shared by some non-consumer members of AHIC, who noted at the July 31 AHIC meeting that members of the AHIC successor would be more likely to act in the interest of their particular industry sector than on behalf of the public good. To mitigate this, we encourage you to require the newly constituted AHIC to have governing rules and by-laws that give consumer and legitimate patient organizations an enhanced role in the decision-making process.

We also strongly urge you to appropriately define what it means to be a "consumer" stakeholder. The White Paper defines members of the consumer sector as "individuals who agree to seek medical or other health care from participating members." We believe that any consumer members of AHIC must not only be individuals who can share their personal stories and interactions with the health care system, but consumer advocates who represent broad constituencies and are able to articulate the wide range of consumer interests in this area.

AHIC Should Have a Secure and Stable Source of Funding, Free from Conflicts-of-Interest

We are concerned that the need to continually seek out new and emerging funding sources will handicap AHIC's ability to develop uniform, coherent policies that are in the national interest. Without a stable, secure source of revenue, the AHIC successor entity will likely have to devote considerable staff time and resources to developing new funding sources – funding sources that could inappropriately influence the development of priorities and recommendations. We are concerned that the need to secure adequate funding could lead the AHIC successor to devise policies that enhance revenue but compromise the privacy of personal health information. For example, assessing user fees on the use of data for commercial purposes could encourage the promotion of policies to expand secondary uses of health data without adequate protections for patient privacy. We believe the AHIC successor would far better serve the public if it has a

stable source of federal funding. This also would make it more accountable and allow it to appropriately focus its staff time and energies on HIT policy.

AHIC's Decision-Making Process Should be Open and Accountable to the Public

The White Paper states that the AHIC successor will not perform any functions that are “inherently governmental.” Yet the duties set out in this White Paper involve important policy questions that cannot be divorced from decisions to set standards, prioritize stakeholder interests, or certify products. We believe these questions would best be addressed through a transparent, open, and accountable process, throughout which the government plays an active oversight and participatory role as both payer and advocate for the public good.

To ensure this transparency and openness, we agree that the AHIC successor should abide by the principles set out in the National Technology Transfer and Advancement Act of 1995 (NTTAA), as noted in the White Paper. These principles are critical to secure the trust of stakeholders, and have been extremely helpful in advancing the work of public-private entities such as the National Quality Forum. Openness and transparency in the decision-making process must include, at a minimum, sufficient notice to the public of meetings, opportunities for the public to attend meetings and provide comments, and publication of clearly written, easy-to-understand materials in an easily accessible way throughout the process.

We also believe that the AHIC successor should be fully subject to the rules set out in the Federal Advisory Committee Act (FACA) to ensure transparency and accountability. This principle is consistent with the policy goals of a key Congressional committee that has taken action on these issues, the Senate Health, Education, Labor and Pensions (HELP) Committee. On June 27, 2007, the HELP Committee reported out a bill that would provide AHIC with statutory authority to serve as an advisory body to federal policymakers on HIT issues. As such, AHIC would be fully subject to FACA rules and Congressional oversight. We urge you to work with Congressional leaders to pass comprehensive HIT legislation and ensure that AHIC is fully open and accountable to the public.

Sincerely,

National Partnership for Women & Families
AFL-CIO
AFSCME
Childbirth Connection
Consumers Union
Department for Professional Employees, AFL-CIO
Health Care For All
National Coalition for Cancer Survivorship
National Consumers League
SEIU