



**National Association of
Community Health Centers, Inc.**

February 5, 2007

Dr. John O. Agwunobi
Assistant Secretary for Health
Office of Public Health and Science
Health and Human Services
200 Independence Avenue, S.W., Room 434E
Washington, DC 20201

Re: Request for Information (RFI): Improving Health and Accelerating Personalized Health Care through Health Information Technology and Genomic Information in Population and Community-Based Health Care Delivery Systems, Federal Register, November 1, 2006.

Dear Dr. Agwunobi:

The National Association of Community Health Centers (NACHC) is submitting the following comments in response to the above RFI.

NACHC is a national non-profit association representing and providing professional support services for Federally Qualified Health Centers (FQHCs) which are also known as Community Health Centers, Migrant Health Centers, and Health Care for the Homeless Programs. FQHCs are private, non-profit or public health care provider organizations that receive grants under Section 330 of the Public Health Service Act from the Health Resources and Services Administration (HRSA) to provide preventive and primary health care and related services in medically underserved communities and for medically underserved populations; or they are organizations that are "certified" as meeting all the requirements to receive Section 330 grants but have not yet been funded.

Summary of Recommendations:

These non-profit community-based health care organizations are one of the largest delivery systems for preventive and primary health care to the medically underserved in the nation and territories - serving 1 in 5 low income uninsured individuals, 1 in 4 people in poverty, and 1 in 9 Medicaid recipients. Given that health centers are such a critical infrastructure for access to care for the underserved, we urge HHS to: (1) immediately take active steps to assure that health center representatives are at the table in all deliberations regarding interoperable health records and Electronic Medical Records (EMR); (2) ensure that overall HHS policy includes a focus on making new resources

available to enable health centers to adopt and sustain the technology required to be full participants in the emerging electronically-enabled health care system. This should include allowing EMR start up and maintenance costs to be included in Medicaid and Medicare reimbursement formulas; (3) ensure that genetic testing and data collection include appropriate safeguards regarding security and privacy of individual patient information and prohibitions and penalties against discrimination against patients with particular risks; (4) ensure that genetic testing and data collection are combined with access to counseling, prevention, and treatment, with full recognition that there may be costs associated for the uninsured; and (5) work more closely with NACHC and other safety net representatives on these issues as they are deliberated and developed at all levels.

Discussion:

There are approximately 1000 FQHCs providing preventive and primary care services in 5700 sites in rural and urban communities throughout the U.S and territories. These health centers provide a "health care home" for approximately 16 million of our nation's neediest patients, most of whom have annual incomes below 200% of the federal poverty level, and 70+% of whom have incomes actually below the federal poverty level. 40% of health center patients lack any form of health insurance to help pay for their health care, 35% receive Medicaid, and 60% are members of minority groups, with Latino/Hispanic the fastest growing segment. Health centers draw their patients from low-income, culturally and linguistically diverse communities which exhibit a higher than average percentage of health problems. Health centers are also one of the few health care providers available in many rural areas.

Health centers range in size from large, multi-site, multi-million dollar operations to small one-site centers, and have varying degrees of sophistication in use of technology. Centers have been active in adopting information technology for a variety of purposes. Many have actively participated in chronic disease management programs that have documented through the use of data registries significant patient health status improvements in diabetes management, hypertension control, asthma management, and other chronic disease areas. This is a significant accomplishment for at risk populations with many financial, linguistic, environmental and other barriers to health status improvement.

Despite these accomplishments, a recent 2006 Survey of Health Center Use of Electronic Health Information, conducted jointly by NACHC, Harvard University, and the George Washington University (not yet published) indicates that centers have low rates of Electronic Medical Records (EMR) adoption compared to other providers. During the period 2002-2003 only 8% of health centers currently reported using a full EMR as compared to 18% of private, office-based primary care physicians and 28% of hospital outpatient departments. As non-profit organizations, 89% of centers report that lack of capital for start up and ongoing support for EMRs is an important barrier to adoption.

Relatively few centers reported genetic testing or counseling on this survey. 2.3% of centers indicated that they provide genetic counseling on site for services other than OB/GYN, while 32.8% said that they do not. Those that provide genetic counseling use both paper and electronic medical records. More health centers report providing genetic testing on site. HIV genotyping/phenotype and sickle cell anemia are the two most common cases of on site testing. 51% of centers, however, report referring for genetic counseling and 49% report referring for genetic testing for breast cancer.

While many centers and their providers recognize that use of genomic data to provide tailored personalized health care has the potential to produce more targeted interventions and better results for individuals, there are nonetheless concerns about the collection and uses of genomic information for individuals. Without stringent and appropriate safeguards regarding privacy and security of the information there is a danger that the information will be used in a discriminatory fashion by employers, insurance organizations, financial institutions, and policy makers as they weigh costs and benefits of decisions. Health centers serve vulnerable, low-income, and disproportionately minority populations, some of whom historically have been the unwitting victims of studies conducted purportedly to advance knowledge, data analysis, and health care improvements.

While the underserved populations served by centers should be part of this exciting new individually targeted approach to personalized health care, the health centers, their providers, patients, and communities served will require appropriate official privacy and discrimination safeguards as a condition of their participation. An approach similar to that used to establish the HIPAA administrative requirement standards should be implemented with time for full and meaningful public comment. It is also important that policies be put in place whereby testing for genetic factors is combined with patient access to counseling, preventive services, and treatment. This is particularly important for the populations that health centers serve because so many of them have insufficient financial means to secure these services on their own.

Despite the concern and requirement for official safeguards, it is important that health centers that constitute an important part of the health care safety net for lower income, uninsured, and at risk populations not be excluded from the advancements inherent in personalized health care. NACHC and health centers are interested in being at the table in discussions and decisions that will open up this new world of better, more tailored and effective medical care. Through the national network of health centers, this important population that is difficult to reach will be brought to the table.

We continue to be concerned that health centers are not fully enough involved in the developments regarding electronic health records and interoperability. We would urge the Secretary of HHS to appoint an appropriate representative of health centers and the health care provider safety net to all levels of Information Technology and EMR deliberations, advice and decision-making. As of this point, such appointments have not been made. We would also suggest that health centers that are the most technologically ready should be the first FQHC cohorts to participate in genomic data

collection (with appropriate safeguards). NACHC could assist in sharing their experiences and lessons learned with less technologically prepared colleagues.

Finally, we think it is important that HHS take aggressive actions to help find the significant amounts of capital that will be required for most health centers to utilize EMRs effectively. Health centers are non-profit organizations that serve as a primary health care home for an important and significant segment of our nation's economically disadvantaged populations. As such, they will require a significant capital investment in IT if they and their patients are not to be left behind in these exciting developments. To aid in that effort, we would strongly urge HHS to work with the Centers for Medicare and Medicaid Services (CMS) to ensure that start up and maintenance costs for adopting EMRs be allowable costs for Medicaid and Medicare reimbursement purposes.

Thank you for taking these comments into consideration. We look forward to working with you.

Sincerely,

A handwritten signature in black ink that reads "Tom Van Coverden". The signature is written in a cursive, flowing style.

Tom Van Coverden
President and CEO