



January 18, 2005

David J. Brailer, M.D.
National Coordinator
Office of the National Coordinator
for Health Information Technology
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Dr. Brailer,

Please find enclosed The Children's Health Fund's response to the Request for Information in regards to the development and adoption of a National Health Information Network (NHIN) as announced in the Federal Register on November 12, 2004.

Founded in 1987, the Children's Health Fund (CHF) responded to the needs of medically underserved children in New York City's homeless shelter system. Since that time, CHF has replicated the program model across the country, creating the National Children's Health Project Network, comprised of 17 innovative pediatric programs in 13 states and the District of Columbia. With an emphasis on continuity of care, these Children's Health Projects deliver quality care to at-risk children and adolescents via mobile medical units, fixed site, school-based and community-based clinics. Since its inception, the network has provided care to over 350,000 medically underserved children in some of the most disadvantaged rural and urban communities in the nation.

Due to the mobile nature of CHF's programs, electronic health records are essential and CHF has developed and maintained an electronic health record system based on the needs of our community health care providers. In serving patients who traditionally would be lost between the cracks of the healthcare system and who would not usually benefit from use electronic medical records, CHF is uniquely equipped to comment on the development of an

NHIN. CHF believes it is imperative that the Office of the National Coordinator for Health Information Technology consider the implications and opportunities for community health providers in developing a NHIN.

Thank you for your time and consideration in this matter.

Respectfully yours,

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Working Definition of a National Health Information Network

Question 1: Please provide your working definition of a NHIN as completely as possible, particularly as it pertains to the information contained in or used by electronic health records. Please include key barrier to this interoperability that exist or are envisioned, and key enablers that exist or are envisioned.

The Children's Health Fund (CHF) considers a NHIN to be a framework through which providers may access medical records from many separate, interoperable automated systems within an electronic network. Inasmuch as an NHIN can and should serve as a framework, community health providers, hospitals and hospital systems should be able to access information from the NHIN, regardless of differences in system operations and requirements.

Electronic health records (EHR) contain medical history and biographical information about each patient. The system even includes information related to doctor's visits, as well as links to doctor's notes. Each medical record entry within the CHF network has templates that are customized to fit the needs of the community it serves. For each of CHF's National Network programs, templates are tailored to the community the program serves with a customized medical record. In New York City, for example, the EHR system is designed to address the needs of clinicians who treat a disproportionate number of asthma patients. The system is customized to allow the clinician to perform a comprehensive examination around asthma.

As the nation's health system transitions to a new, widespread medical record interoperability, CHF believes that it is essential to ensure that low-income families derive equitable benefits from national initiatives. It also is critically important that financially challenged community-based and not-for-profit entities receive grant funding or low cost capital to invest in costly EHR systems and receive sustained funding.

Transient populations, who include the homeless, create a convincing argument for EHR. One characteristic of a homeless family is that they move quite often within a metropolitan area, making it extremely difficult for these families to retain the same primary care physician, and when they do find a new primary care physician, their paper medical records are not automatically forwarded. However, as there are other issues with which to contend, homeless families may not be proactive about ensuring that their medical records are forwarded to the new physician. With EHR, medical records follow the family and are easily accessible to various providers who treat these populations whether on a mobile medical unit or at CHF's partnering hospitals.

In CHF's experience, resistance by traditional administrators of healthcare within our network has been a barrier to implementing an electronic health records system. The human comfort level with computers and the departure from old record keeping methods must be addressed when considering the development of a NHIN. To overcome this barrier, the CHF National Network provides training sessions to educate providers and administrators. CHF's system follows the intuitive thinking of a healthcare provider in entering and accessing information. To address this barrier, ONCHIT must consider the

professionals and administrators who will access the NHIN on a daily basis to make the system intuitive and seamless.

A key enabler to the NHIN includes the overwhelming desire by many providers of health care to medically underserved populations to acquire the electronic health record technology. These providers want the efficiency and convenience that EHR would provide. That same desire to create efficiency and convenience in health care is shared by government officials. President Bush has expressed his support for widespread interoperability when he signed the Executive Order calling for such last spring.

The NHIN Model

Question 2: What type of model could be needed to have a NHIN that: allows widely available access to information as it is produced and used across the health care continuum; enables interoperability and clinical health information exchange broadly across most/all HIT solutions; protects patients' individually-identifiable health information; and allows vendors and other technology partners to be able to use the NHIN in the pursuit of their business objectives?

The Children's Health Fund's EHR model protects patients' individually-identifiable health information by providing technology designed to meet regulatory standards and then integrates it into clinical environments governed by federal and local standards of practice. Patients' privacy rights are protected by controlling access by different levels of security clearance. A model-based on a Public-Key Infrastructure security model should be considered for a NHIN, where keys would determine tiered access to information contained in EHRs.

Health Insurance Portability and Accountability Act of 1996

Question 7: What privacy and security considerations, including compliance with relevant rules of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), are implicated by the NHIN, and how could they be addressed?

To comply with HIPAA, The Children's Health Fund has undertaken diligent review of software to ensure that, within comprehensible structure of HIPAA law, the system provides adequate auditing trails and logs and supporting systems and provides appropriate levels of data security and encryption. The CHF National Network staff members work with programmatic patient data and supply systems, that stem from CHF's electronic health record system, to direct service providers. At a human resources level, all CHF National Network employees are covered by agreements between CHF and its partner organizations, hospitals, to comply with institutional HIPAA and related regulations. This standard is extended to all CHF sub-contractors.

Going forward, a set of documented standards and practices must be created to link NHIN activities to HIPAA and other regulations. A cook book approach would allow software developers to consistently program and deliver relevant technical protections. It would

also allow those acquiring enabling software technologies a readily understood set of guidelines to evaluate given products. Finally, broad, clearly enumerated standards and practices would provide a measure of legal protection for those developing, producing, and those using NHIN technologies.

NHIN Utilization in Lower Income Rural and Urban Areas

Question 11: How could a NHIN be established so that it will be utilized in the delivery of care by healthcare providers, regardless of their size and location, and also achieve enough national coverage to ensure that lower income rural and urban areas could be sufficiently served?

The Children's Health Fund National Network provides health care in lower income rural and urban areas through our 17 programs in 13 states and the District of Columbia. This focus on medically underserved areas stems directly from CHF's mission. The incorporation of electronic health records varies by program due to partnerships with local hospitals and health systems. CHF developed the framework and continues to innovatively adjust the EHR system to adapt to growing needs.

The New York Children's Health Project is a good example of the how electronic health records have been utilized in an urban area. This program provides care at various locations throughout the city for medically underserved populations via several mobile medical units and a stationary clinic in the South Bronx. In partnership with local hospitals, medical records follow patients as they navigate the shelter system in New York to find permanent housing.

The Mississippi Children's Health Project serves an equally medically underserved population, but patients in this program are spread throughout a rural three county area in the Northwest Mississippi Delta Region. The electronic health record system is different from the New York program and tailored for compatibility with the partnering hospital in Mississippi. When a patient seeks medical care that is beyond the scope offered by the mobile medical unit, their records are available to doctors at the affiliated hospital.

The first step for successful incorporation of EHR systems by providers of care to medically underserved populations is for a detailed schematic for the NHIN to be developed and published. This schematic will need to detail the exact level of interconnection and the information managed through given processes. Current discussions about the NHIN take place at the level of high concept, simple diagrams, or highly detailed technical standards. While healthcare providers appreciate the concepts being proposed, the finer detail and a clearer sense of the actual process for proposed operations must be established to assure providers that the vital clinical considerations have been addressed. In addition, clarification will allow economic expectations to be estimated, justified, and prepared.

A real measure of the success of NHIN will indeed be how the related industry develops. If a significant industry develops to interpret NHIN, rather than to implement and support

it, the proposals lack clarity and cannot be truly engaged by health care providers focusing on care, rather than technology. This is relevant to the needs of such providers whether urban or rural. The unique needs of rural practitioners can be separated into two categories: (1) access to infrastructure and (2) access to a network of support. Local, State and Federal government support to address the unique issues faced by rural providers should be considered when developing the NHIN. These supports should be directed toward rural telephone and data networks. Inasmuch as these supports can be translated to urban areas, where the advancement of technology infrastructure and low-density of health care providers create a conceptually analogous environment to the rural experience, they should be explored.

Community and Regional Health Information Exchange Projects and NHIN

Question 12: How could community and regional health information exchange projects be affected by the development and implementation of a NHIN? What issues might arise and how could they be addressed?

Community health centers have the potential to act as the starting point in a patient's continuity of care. As a front line provider of care, records retained at the beginning of a patient's interaction with the health care system or beginning of life will be indispensable when emergency care is needed at a larger well-funded health care provider. Therefore, such centers could significantly benefit in terms of meeting their missions through this process. Issues that may well arise may be classed in a number of ways; financial, human capital, management and program longevity.

The obvious issues are financial. Experience suggests that 10-15% of a clinics operating budget goes to support their own technology costs. How a community or regional HIN would impact them could be significant. Budgets for community and regional health information projects are under pressure already, the development and maintenance of another layer of technology puts yet another pressure on finances and employee time. The level of administrative work involved with upkeep and updates to the HIN is largely unknown, but must be considered when assuming widespread implementation of the HIN as smaller operations will be strained more so than larger systems and hospitals.

Likewise, questions of HIN management, ownership, and potential proprietary aspects could strain individual centers resources in terms of understanding and sophistication about a highly technical, but vital link. One response might be to develop community and regional centers using a model similar to the New York State Education and Research Network (NYSERnet), an educational computing consortium. This service provides coordination, to a specific region, of educational information by providing a technical infrastructure in a semi-public mode as well as operational transparency and content independence.

Interoperability Standards to Address Privacy

Question 15: How should the development and diffusion of technically sound, fully informed interoperability standards and policies be established and managed for a NHIN, initially and on an ongoing basis that effectively address privacy and security issues and fully comply with HIPAA? How can these standards be protected from proprietary bias so that no vendors or organizations have undue influence or advantage? Examples of such standards and policies include: secure connectivity, mobile authentication, patient identification management and information exchange.

The government must establish a process of standards development, publication, comment, and ratification for the NHIN to comply with existing statutes. The period of comment process allows interested parties to provide comment and input for proposed standards and to submit draft suggestions for review and process.

The greatest challenge in terms of privacy and HIPPA is the need for clear comprehensive HIPPA guidelines. These guidelines would be explicitly linked to the electronic management and communication of information. A set of protections should be implemented for smaller clinics and providers. These protections would allow clinics engaged in the implementation of electronic health records to be insured against liability for violating HIPAA at a software level if they were demonstrably misled about quality and thoroughness of compliance by the vendor. This would not shield them from other HIPAA and privacy expectations.

Financial and Regulatory Incentives and Legal Considerations

Question 19: Are financial incentives required to drive the development of a marketplace for interoperable health information, so that relevant private industry companies will participate in the development of a broadly available, open and interoperable NHIN? If so, what types of incentives could gain the maximum benefit for the least investment? What restrictions or limitation should these incentives carry to ensure that the public interest is advanced?

Financial incentives for community health centers should be a priority. Private entities and businesses are already benefiting from the development of EHR systems at well-financed health care systems and hospitals. From a regulatory perspective, the NHIN has the potential to take on a significant strategic quality, as has the Internet both at a national and humanitarian level.

The Office of the National Coordinator for Health Information Technology should consider requiring those who wish to integrate their EHR software with the NHIN to place their software code in a national escrow system so that should they lose or end their support of the product, those individuals and organizations dependent upon the specific software have some recourse to continue its development or maintenance. This would significantly offset the dangers to those who invest in these products to meet a federal directive at no significant expense to private enterprise. If a company ends its relationship with a product, it can sell the product to another company.

Question 20: What kind of incentives should be available to regional stakeholders (e.g., health care providers, physicians, employers that purchase health insurance, payers) to use the health information exchange architecture based on a NHIN?

Grants to community health centers, and model programs, must be created to establish, maintain and operate electronic health record systems. Many federally qualified health centers would prefer to have electronic records but simply do not have the resources for the technology or the operations capability to maintain such systems. Maintenance of the systems, as well as updating the information on regulatory changes and diagnostic changes needs to be considered when developing a grant-driven program. While encouraging initial acquisition is important, significant stress, and ongoing use and cost of ownership, are poorly anticipated factors. Incentives that would support this ongoing challenge would have a great impact, though they need not be direct financing. If systems were devised at the local, regional, or national level that allowed clinics to share operations with each other, then the load could be shared; off-setting not only the financial burden, but the sense of isolation non-technicians often face when confronted by intensely technical situations.

A collaborative and cooperative model for community health providers should be considered to achieve sustained access, and use of, the NHIN.

Question 24: How could success be measured in achieving an interoperable health information infrastructure for the public sector, private sector and health care community or region?

The success of The Children's Health Fund's Electronic Health Record (EHR) system is measured in several ways. The most apparent success is the widespread use of the EHR system by CHF National Network providers. When providing care on a mobile medical unit to a medically underserved population, paper records were impossible to maintain. The ease with which CHF doctors, nurses and administrators use the system makes providing care to children and families timely, accurate and patient appropriate.

Success in achieving interoperability of a NHIN must be measured at all levels of healthcare, including community health care providers, hospitals, health care systems, insurance companies, state Medicaid and Medicare programs and long-term care facilities. If one of these pieces of the health care puzzle does not, or cannot, implement the use of electronic health records, then the continuity of care for a patient is disrupted and the system fails. A record that is not accessible to one entity within the health care system is not useful when that patient visits or tries to access the services from that entity.

Another danger to the success of a NHIN is the potential technological disparity that exists among providers. The lack of finances and human resources to operate systems to access the NHIN will prevent implementation of electronic health records for certain providers. This disparity will grow as the technology develops.

Improving the health status of all Americans should be the foremost impetus for developing a NHIN and for use of the NHIN by public and private entities and the

healthcare community. To the extent that electronic health records provide continuous patient care, a NHIN would improve the health status of patients by fostering the use of electronic records across regional and community boundaries. Unfortunately, this is a vague benchmark by which to measure. One way to measure this factor is the level of use and access by healthcare providers for decision making and quality of care review.

While broad-based studies offer a variety of means to measure the efficacy of such materials, in the field of pediatrics, collaborative work with school-based health programs could provide a comprehensive, consistent means to implement and test hypotheses dealing with the use of electronic health records.