



Center for Health Transformation
Better health, lower cost

An American Electronic Health Record Should Be Created in 2004:

A Report on the English Electronic Health Record

Center for Health Transformation

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When the new benchmark Medicare physical at 65 is launched in 2005, it can and should be recorded in an electronic health record, on behalf of the patient, using an encrypted, HIPAA-compliant, Web-based, nationwide system. This Electronic Health Record (EHR) would belong to the patient, but could (and likely would) be available to healthcare professionals for medical work and for administrative and legal purposes. A properly-designed Web-based system is compatible with virtually all legacy computer systems in doctors' offices and hospitals and can be operated using minimum bandwidth over normal telephone lines.

A Medicare Electronic Health Record will revolutionize our ability to: detect disease, ensure needed co-morbidity management, detect fraud, increase compliance for patients with chronic disease, accelerate the development of best outcomes and identify doctors whose patient focus might justify specialized continuing medical education and information about the newest best practices. One immediate effect of an Electronic Health Record will be a significant decrease in unnecessary tests because doctors will be far more likely to be able to diagnose a patient's problem knowing what medications they are taking and/or knowing the patient's most recent diagnoses. Similarly, a significant number of tests and exams are performed because the results of tests already performed are not available to the next practitioner. The number of such unnecessarily repeated tests will plummet when every healthcare professional can share the results of one test instead of many professionals asking for it again and again.

Medicare Electronic Health Records will save lives, improve the quality of life, and lower costs all at the same time. They can be acquired and tested during 2004 and launched with the first Medicare benchmark medical exams for new Medicare participants in January, 2005.

From day one, the new Medicare Electronic Health Records could be integrated with existing PBM-based electronic medication data with an immediate saving of lives and money by avoiding medication errors, detecting fraud, and enabling expert systems to evaluate health conditions and warn patients and doctors of impending dangerous and more expensive problems. These health savings and budget savings will literally start the first day the health record and the medication record are connected.

An Electronic Health Record is relatively more valuable for older Americans because the elder population has more medical conditions and tends to have much more complicated health challenges than younger people. Proportionately, more mistakes can be avoided, more lives saved, and more bad outcomes avoided among older Americans in an intelligent health system than would be the

case with the same number of young people. Thus, Medicare is the right place to launch an electronic health record to get the maximum impact from President Bush's program for "saving both lives and money". By making this electronic record available to the patient, we empower what Dr. Anthony Nowlan calls "the greatest untapped healthcare resource—the patients themselves."

There are literally thousands of systems already in use in the US to help manage health care delivery. It is thus vital to have an interface strategy that is able to use presently-available standards and approaches to allow all legacy systems to source information to the Electronic Health Record without major changes in such systems. It would be wrong to follow a 'rip and replace' strategy because it would be far too expensive and will take far too long.

British medical experts believe it is possible to install a core system for a successful electronic health record now, and then over the years add more components. They argue the key is to get it running and being used as quickly as possible.

The result is an enormous step toward developing a 21st century Intelligent Health System.

Since the British are currently deploying such a system after years of work in identifying and vetting those who can deliver it, they are already demonstrating that in the US an Electronic Health Record can be developed in 2004 and launched in 2005.

On February 5, 2004, our team met in London with participants in the development of the British electronic health record.

The British National Health Service (NHS) is currently deploying an electronic health service for 55 million patients in England. The first components will be on-line for some doctors in June, 2004. All major components will be on-line by December 2004.

This is the first national electronic health record in the world of this scope and scale. It is the necessary proof of concept that enables American decision-makers to move forward decisively with confidence that the technical issues are manageable and that the capacity to create and sustain an Electronic Health Record already exists. Furthermore, the key public policy issues of confidentiality, ownership, and nature of the information have already been thought through in a multi-year process by the British National Health Service.

IBM has already run a proof of concept pilot electronic health record with 184,000 patients based around one local health community including a hospital. It took IBM five months to assemble and to launch the electronic health record pilot, and it was scalable from day one. IBM with their partner HealthTrio, Inc. also assembled, demonstrated, and tested the complete solution for a national electronic record as part of their involvement in the NHS procurement.

HealthTrio, Inc. helped think through the critical distinction between an electronic medical record (a huge volume of detailed, time-limited information, most of it needed for administrative and legal reasons) and an Electronic Health Record (a much more focused system construct that includes the key information a patient or doctor needs to know for on-going care). HealthTrio also developed the Health Information Model, which allows the system to extract key data from a wide variety of legacy systems, encode and understand it and then support it on the Web as an Electronic Health Record. IBM and HealthTrio are both confident of the ability to create and sustain an encrypted, HIPAA-compliant, secure, Web-based system with minimum bandwidth requirements providing the ability for every patient, doctor and hospital to access the information in a secure manner without having to replace their legacy computers. This was vetted during the extensive proof-of-solution trials in the UK.

Detailed Report on Meeting with Specifiers of the British Electronic Health Record System and Developers of Proof of Solution

FEBRUARY 5, 2004. In early February, our team met with Dr. Anthony Nowlan (until recently Director of the NHS Information Authority and described as the intellectual developer of the specification for the English electronic health record), Christian Noll (the IBM director of the National Health Service Business), Simon Stone of the IBM Healthcare Practice, and Mark Stevens of HealthTrio. Earlier we had been briefed in detail by Dr. Ralph Korpman, President and CEO of HealthTrio, who had a long period of work in the UK drafting the specifications of the English electronic health record. Ralph has been developing a proposal for an American Electronic Health Record as a project with the Center for Health Transformation and it was he who identified the people who were invited to the meeting.

In addition to the British program, it was suggested we should look at developments in Hong Kong, where they are working to develop a Hong Kong Information Interchange for healthcare.

The implementation of a core national electronic health record is part of a wider (but separate) program for IT in the English NHS which also includes the

provision of specialized hospital and community systems and a new network infrastructure for NHS-managed care facilities.

The local delivery component of the program has been contracted with five Local Service Providers (won by Accenture x 2, CSC, Fujitsu, and British Telecom). But there is a single national application service provider delivering the national electronic health record for the 55 million patients in England (referred to as the 'spine record'). The use of the national record is not limited to NHS-managed providers and can be made available whenever and wherever an individual receives care.

The driving force behind the rapid development and launch of the National Programme for IT and the electronic health record in particular was Prime Minister Tony Blair's requirement to have visible improvements in the National Health Service (NHS) in a very short period of time.

Derek Wanless (former CEO of the National Westminster Bank) had done a review in early 2002 for the Treasury of long-term trends affecting the health service in the UK'. Importantly, this report was not commissioned by the Department of Health (the Ministry responsible for the NHS) but by the Treasury, which was used to dealing with electronic financial information.

Wanless noted that the use of information and communication technologies in the NHS was poor. He emphasized that the NHS urgently required modern integrated information systems to operate efficiently and effectively, including an electronic health record.

The NHS has made significant investments in research and development-related activities over the years but has not seen large scale coordinated investment in implementation. Prime Minister Blair rejected proposals to delay the development of the electronic health record until various standards might be developed and perfection obtained and insisted it be launched within a three-year window. The American launch can be substantially faster because of the work already completed in Britain.

Dr. Nowlan emphasizes that the electronic health record is about the individual and is best thought of as a system to support the care of one patient at a time and not as a system to run a national organization. Since patients come one at a time, programs are made unnecessarily complex and costly by designing them to serve a multiplicity of competing demands rather than remaining focused on the main purpose: the care of the individual. He suggests that thinking it through for a single patient makes the process far more manageable. Then, it can be scaled up to the national capability where the main issue becomes simply the number of

different institutional systems that may require some kind of interface. The interface issue is straightforwardly addressed by systems that are designed to integrate all received information from a multitude of sources around a single Health Information Model designed to support the Electronic Health Record.

Nowlan notes that healthcare has been institution-centered since the birth of the clinic around 1800 and cites Roy Porter's description of how the sick man became a patient and disappeared in the equations of health economics, sociology and diagnostic technology¹. For the last two hundred years 'health care system' has been synonymous with the organization of the institutions within it. The institution can be a sole practitioner doctor, a laboratory, a large complex hospital or a variety of other forms, but invariably the ways the 'system' works and the information within it center on the institution's experiences and needs. Nowlan asserts that while it is necessary to support institutions and professionals, it is not sufficient for modern health and health care. All of the major challenges facing health center on the experiences of the individual – the health care system as a personal experience. It is the individual's experience of health that should be the center of the workings of care and the information supporting it. He also asserts that today, for the first time, we have the information technologies that enable us to construct and manage the individual's health experience in a virtual form, no matter how many institutions they visit.

¹ The Greatest Benefit To Mankind: A Medical History of Humanity by Roy Porter, WW Norton & Co, 1997.

Nowlan describes how a patient with cancer that also has other problems (co-morbidities) can visit as many as 30 different professionals in five different institutions in a two-year period. Today, such patients either have incomplete records with all thirty professionals and five institutions (the American model) or they have paper documents trailing along behind them via mail (the British National Health Service model). With a patient-based Electronic Health Record, both the patient (via a Patient Health Record) and the professional have full information instantly available. Portions of this already exist in the American Veterans Administration electronic medical record system and are being rolled out starting in 2004 in the Tricare electronic medical record system for the Defense Department.

A paper system is by definition unconnected. With co-morbidities, the paper system guarantees that over a year or two the same information is collected again and again. Eliminating this unnecessary duplication of effort is a significant savings that more than pays for the Electronic Health Record.

The "common information system" (the Electronic Health Record) needs to be inter-operable with much denser specialized information systems (such as those

for radiology reporting) and with specialist electronic medical records systems. Properly designed to contain a distillation of information from these systems, and architected to support the particular needs of a Personal Health Record and an Electronic Health Record, this compatibility is demonstrably achievable.

Creating an Electronic Health Record allows the setting of a new and much higher standard for the information that should be available before any safe service is offered to a patient. In effect, it creates a new plateau above which there is safe medicine and below which there is malpractice.

Doctors must be able to have faith in the quality and provenance of information they are reviewing. An unidentified piece of data is inherently an untrustworthy piece of data. It is essential that information be tagged by the source so it is known who put it in the record, where and when. As patients create an increasingly significant portion of their own records, this becomes even more important.

It is well-established how to create mutual trust between professionals and patients in a local setting where personal relationships can be built. It is a new challenge to develop mutual trust in a distributed electronic environment. Thus, the mutual trust has to be designed into the system. This issue of mutual trust and who guarantees that trust goes hand in hand with patient confidentiality in making the system usable.

Both doctors and patient groups helped define the information that needed to be managed by the Electronic Health Record. The requirements were placed into four broad categories:

1. Demographic information including personal information such as whether you come by bus, who to call if you can't explain your problem (e.g., car wreck, stroke, etc.), the language in which you communicate (for Britain as well as for the US, this is now important information);
2. Caregiver information, in particular those currently involved in providing care;
3. Event information (when you were discharged from the hospital, etc.); and,
4. Summary health and wellness information (your current health status including medications and significant health issues/problems).

Any health professional can input data, but it has to be tagged with its provenance (who, when, where, etc.) so it can be judged in context, just like is done now with paper records and letters. Reducing all input information to a common model makes this process facile and supports all health participants.

Health professional users will interact with the health record through a mix of two strategies:

1. Using an existing (or later purchased) specialist system that communicates with the Electronic Health Record so there is no lag time nor lost information; and,
2. Using a set of basic tools for health professionals which work directly on the Web with the Electronic Health Record to support access from any location.

For individuals (patients) as users the health information is appropriately presented and interpreted. Many patients will be reading this kind of material for the first time, and they need a Web-based question and answer capability or they will drown the doctor in phone inquiries the first time they read the record. Work in the UK on providing patients direct access to their health records brought out simple examples of the sorts of problems that can arise. Patients saw the results of routine testing of urine samples for infection which read “No growth found”, meaning no bacteria were grown. Some patients however interpreted this as the doctor was looking for cancer – a malignant growth, causing them concern and prompting calls to their doctor’s office. Care with use of language and the provision of explanatory links can help prevent this.

The patient portal into the NHS Web system is called NHS Direct. That might become “Your Medicare” in the American model.

Extensive work has been done by the NHS on patient confidentiality; interestingly, the UK issues are very similar to those in the US. Peoples’ responses to proposals for managing their information depend on their personal and health circumstances.

In the NHS focus groups, people were generally trusting and supportive of clinical professionals, in particular doctors, but distrusting of ‘external’ agencies such as insurance companies and administrative people in terms of where their information could go. Patients with what is typically considered to be ‘sensitive’ health information, such as HIV/AIDS, were concerned that doctors knew their health status when they went for treatment, particularly in an emergency room, because it could be life threatening to make decisions without being aware of their condition and their existing treatments.

In the UK, patients have rights in law over their information and its use, but providers have the right to copy it electronically for their own administrative and legal needs. Various security and privacy parameters and the addition of “sealed

envelopes” of information the patient deems particularly sensitive have addressed the vast majority of concerns.

Interestingly, many people in Britain thought there already was an electronic health record because so much of their material had gone into computers. They were surprised to learn there was not one.

There is a long history in the NHS of debating smart cards for patients versus a Web-based system. The smart card can be a key to access or a backup if the network connectivity breaks down, but it is not an alternative to a Web-based Electronic Health Record system. A key reason the information has to be on the Web is that multiple physicians, nurses, and lab specialists may be using the information at the same time. In fact, most patient information is used when the patient is not present.

A smart card is not part of the current English electronic health record.

Implications of the NHS Experience for the US Electronic Health Record

The new US national Electronic Health Record contemplated here should begin with new data and will not go back and pick up the historic data (at least initially) unless it is explicitly relevant to a current health condition.

One key reservation about loading in historic data (paper or electronic) is that it is not always clear how accurate and reliable such information is; most investigations have raised huge questions about the reliability of records, and the provenance of data is also often uncertain. There must be a very high premium given to ensuring that the new Electronic Health Records are accurate and trustworthy.

The new Electronic Health Records will be created initially with an interview of the patient that creates a baseline history, physical, and personal data set.

It is important to connect the Electronic Health Record with pharmaceutical benefit systems to ensure complete and correct information on medication. The financial claims system should also be synchronized with the Electronic Health Record so they become mutually validating. Medicare intermediaries and Carriers already have key information (diagnoses, treatments, etc.) in electronic form.

There is adequate time left in 2004 to ensure that both patient self-assessment and the professionals’ interview protocol can be specialized for specific disease

problems so doctors would have best practice models of what information to be gathering in specific disease states.

If doctors already have electronic practice management and appointment systems, it is possible to integrate them with the Electronic Health Record; however, one must remember that the EHR must not be used to try and run all of the organization. We are first interested in managing the patient's personal health care interactions, not the hospital's workload. Other disaggregated examples of electronic data gathering are also available for the Electronic Health Record at little or no additional cost (e.g., electronic lab reports).

The NHS is evolving into an HMO-like system (in the true sense and not as a cost containment organization like many have become in the US) which will pay for a variety of service providers (public and private including providers outside the country). The UK Secretary of State for Health said "what matters is the care provided and not who provides it". There is a growing 'plurality of providers' instead of the unitary NHS provider structure of the past. Private providers are actually growing much faster than private insurance. This deconstruction into multiple providers will actually make the Electronic Health Record of greater value since people will have many more choices about where to go for their healthcare.

It is vital to have an interface strategy that uses current standards, systems, and approaches to allow all legacy systems to operate without replacing them. It is wrong to follow a 'rip and replace' strategy because it is far too expensive, would take far too long, and misses the point which is to make the shift from a purely institution-based approach to one with a strong person-based component.

It is possible to build a core system for a successful Electronic Health Record and then over the years add more components, interfaces, and functions. The key is to get the Electronic Health Record operational and used as quickly as possible. Doing this helps people understand its purpose and how they can use and develop it, and will thus help them shape the changes in practice that parallel the systems development

If one builds a narrative for a patient with complex co-morbidities (such as a cancer patient) so people can see the complexity of information flow without an Electronic Health Record, the result is frightening. Clearly the paper system cannot hope to cope with the complexity. A properly modeled Electronic Health Record enables tracking of the patient's journey through multiple interventions and multiple institutions. It allows information to be truly centered around the patient for the first time.

If the ability to document care is established, then rules-based pathways, best clinical care, and other outcomes-based models can be combined with search engines to scan the Electronic Health Record (including the medication record) to find people who are not getting the right treatments.

The Electronic Health Record-medication synchronization allows measured compliance for the first time. A doctor's records only note that a prescription has been written. There is no record of whether a prescription has been picked up, much less whether renewals were timely refilled. The PBM medication record at a minimum helps focus on those who did not even pick up their medication. If the prescription is monitored for compliance via the Electronic Health Record, over time the absence of reordering, or the time between reorders, gives further compliance data and helps coach the patient toward better outcomes. The failure to pick up a medication can be flagged so the doctor or nurse can call the next day and see if the patient is better or needs to be encouraged into immediate compliance. The possibilities are endless. This clearly has significant implications for treating people with impaired capacity to care for themselves where compliance can be a lifetime challenge.

According to the British National Health System analysis, eliminating redundancy in lab requirements, data gathering, interpreting conditions combined with the certainty that the information will be available reduces waste and frees up clinicians to focus time on the patient.

The ideal system will respond in less than one second and have high reliability. However, it is vital not to establish reliability standards at the level of the NASA shuttle. Every additional tenfold increase in reliability raises the price of a system dramatically. The goal is to have a system that is virtually always available, but that might be out of commission for short time periods rarely. It is likely that 99.99% uptime (unavailable for no more than 15 minutes per 24 hours) or 99.999% uptime (unavailable for no more than about a minute a day) will be more than adequate for the Electronic Health Record.

The goal of the Electronic Health Record project is to not lose the good in pursuit of the perfect; having more users getting more benefits every day is what is most desired. That is why the Electronic Health Record must run effectively over voice-grade telephone connections. That is also why the NHS learned that it is essential to start with current understanding, established practices, and available solutions and then get the clinical professions and patients to build the protocols and work forward from there. "You cannot require everybody to change everything before we have anything", Dr. Nowlan notes, "It is an invitation to failure to try to start with a blank slate." The key is to move the technology and the clinical professionals, patients (individuals), and health services managers in

parallel and not to try to be sequential. Mutual trust is therefore important, supported by appropriate governance.

About the Center for Health Transformation (CHT)

The Center for Health Transformation, founded by former House Speaker Newt Gingrich, is a unique collaboration of leaders dedicated to accelerating the adoption of transformational solutions, policies and technologies in order to create a 21st Century Intelligent Health and Healthcare System characterized by better outcomes and more choices at lower cost. The Center accomplishes this by: acting as a catalyst to accelerate transformational change; identifying better solutions that provide more choices, better health and lower cost; sharing those solutions with the widest array of opinion leaders and decision-makers across all sectors and levels to accelerate their adoption by the system; and helping to create, advance and improve the public policies (state and federal) that will accelerate health transformation.

For more information, please visit www.healthtransformation.net.