Building Trust and the Privacy Concerns of a National Health Information Network

Now is the Time to Act

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Similar to the platform of her husband's presidential campaign in 1992, the front-runner for the Democratic nomination in the 2008 Presidential Election is promising to establish a plan for universal health care for all Americans. And if Senator Hilary Rodham Clinton (D-NY) is elected in November of next year their will be more than just the precedence of the nation's first female President, but like her husband their will be a committed Commander and Chief who plans to prescribe antibiotics to the failing healthcare industry. Today this industry is in much need of such a prescription of public policy since 47 million American men, women, and children are currently uninsured.[i] This staggering number exceeds the populations of Arizona, Arkansas, Colorado, Iowa, Kansas, Louisiana, Mississippi, Missouri, Montana, Nebraska, North Dakota, Oklahoma, South Dakota, Utah, and Wyoming combined.[ii]

Former President William (Bill) Jefferson Clinton, saw this growing epidemic in the early 1990s and fought for universal health care coverage like Harry Truman in 1945.[iii] During Clinton's first week in office he followed through on his campaign promises and established the White House Task Force on Health Reform.[iv] He appointed First Lady Hilary Clinton to spearhead the initiative, which planned to create a national health care program that would guarantee insurance for all Americans. Unfortunately this initiative did not offer the desired results Bill and Hilary Clinton had promised, but at no fault to their work. They were faced with partisan hurdles in Congress and a raging lobbying and advertisement campaign by the for-profit insurance industry that they could not leap passed. Years later on March 26, 2007, in a town hall meeting in Iowa

to promote her Presidential candidacy, Mrs. Clinton stated that the country is in a "better position today than we were '93 or '94 to obtain universal health coverage." [v]

Today, the nation has popular and bipartisan congressional support for the issue as health care prices continue to escalate and more people are forced to become uninsured. In addition to the social movement taking place by the citizenry and in the halls of Congress, improved information technology offers greater technical opportunity for utilizing and managing a comprehensive National Health Information Network (NHIN). Such advantages offer Mrs. Clinton the opportunity to create a program that reduces costs for insurers that will trickle down to consumers; protects the privacy of all American citizens' health information; promotes trust, which will foster the increased use of the system and reciprocate an increased value of the tool; and most importantly save potentially thousands of American lives and improves the quality of millions more.

Although the plans of President Bill Clinton's White House Task Force on Health Reform were never implemented, the administration was successful on other health care policy fronts during their eight years in office. Perhaps the most important was in 1996, the Health Insurance Portability and Accountability Act (HIPAA) was passed by the 104th Congress, which improved the "portability and continuity of health insurance coverage in the group and individual markets, to combat waste, fraud, and abuse in health insurance and health care delivery." [vi] Through the delivery and prevention of waste or fraud, HIPAA "directed the nation's health sector to move by the early 2000s to electronic systems for

processing medical treatment, claims, and administrative data" thus maturing into a 20th century Web 2.0 electronic health records (EHR) standard and moving away from the error laden and inefficient paper-based system that had been used for decades while innovations in technology were being ignored.[vii]

Hilary Clinton developed her argument of why America needs a universal healthcare system in the March 2007 Iowa town hall meeting, saying that the U.S. spends more money than anyone in the world on healthcare.[viii] Although the U.S. is spending the most money in the world, a lot of it is wasted in redundancies and errors due to the inefficient tools prevalently used throughout the medical and health industry. Among nations in the Organization for Economic Cooperation and Development (OECD), the health spending by the United States is two and a half times the per capita median of other OECD countries – that equates to $1.7 trillion or 15-percent of the total U.S. Gross Domestic Product (GDP) – versus the eight-percent OECD average.[ix] Analysts have projected this trend to continue to rise and that 20% of the U.S. GDP will be directly spent on health care by 2015 - 2020.[x]

Although the U.S. spends the most, the nation is currently mismanaging the allocation of its funds compared to other nations' health expenditures. Therefore, the country could either save money or reallocate funds to better serve the needs of citizens and the industry today. Furthermore, and as a separate issue, the industry's failing legal malpractice problems have haunted the industry where "ten cents on every health care dollar paid by individuals or companies goes for litigation and defensive medicine." [xi] This too must be

rectified, but that is not dependent on an NHIN or another technological solution and would require separate legislation to amend the law.

A significant percentage of the health expenditures in the United States are wasteful or duplicative. As shown by the malpractice issue, keyboards and integrated circuits cannot fix the entire industry but ignoring the benefits that can directly come from an investment in Health Information Technology (Health IT) is shameful for policy makers. HIPAA directed the country to adopt EHRs in 1996 but the U.S. still spends only $0.43 per capita on Health IT. [xii] This paltry sum is only slightly more than the price of a United States Postal stamp. Contrarily the United Kingdom spends $192.79 per capita and Canada – with a similar population and geographical citizen diffusion than the U.S. – spends $31.85 per capita.[xiii] By looking at how these countries utilize these expenditures, the U.S. can improve its service to its citizens by reducing the wasteful spending.

On June 16, 2005, U.S. Senate Majority Leader Bill Frist (R-TN) and Senator Clinton introduced the "Health Technology to Enhance Quality Act of 2005" (Health TEQ) which planned to create "an interoperable health information technology (IT) system through the adoption of standards that will help reduce costs, enhance efficiency and improve overall patient care." [xiv] Although in the best interest of the citizenry of the country, and with Senatorial bipartisan support, this bill that planned to bridge the gap between the U.S. and these other OECD nations in Health IT spending died in the 109th Congress. Thus it was never enacted into law, but Senators Clinton and Frist have pledged to reintroduce it in the 110th Congress. Numerous other Health IT bills in similar

scope to the Clinton-Frist plan that were introduced in both Houses of Congress that also benefited from bipartisan support suffered the same fate in the 109th Congress due to political infighting rather than governmental priorities.[xv]

The RAND Corporation has concluded that if utilized effectively a widespread American EHR system, similar to the Clinton-Frist bill, could reduce wasteful American health spending by $162 billion annually and could save the country $346 billion dollars annually if anonymous cumulative data were available for researchers to study and analyze healthcare trends for the prevention, protection, and improved response to outbreaks of diseases and health emergencies.[xvi] The $162 billon savings are shared between the reduction of duplicative procedures; improved safety, such as automating an alarm system for doctors and pharmacists for any potential conflicts to diagnosed prescriptions; and earlier detection and treatment of chronic diseases. [xvii] Today the expenditures of the long term treatment of chronic diseases equates to 75% of all healthcare expenses.[xviii] And with 20% of the U.S. population accounting for 80% of the health spending by the country, if early detection of chronic diseases alone were made easier by the vast adoption of Health IT, a fractional drop in the three-quarters spending of $1.7 trillion could equate to billions more saved.[xix]

RAND believes that paper records should not simply be digitized and stored on a computer, but an interoperable and standardized NHIN should be created. This will create the synergy of a networked effect to improve the health care industry. Senators Clinton and Frist want to, "implement standards that are

mandatory across federal government programs, and voluntary for private sector"
adoption with their Health TEQ bill to spark this synergy.[xx] President George W.
Bush agrees.

In following in the leadership of his predecessor Bill Clinton, President
Bush created the Office of the National Coordinator for Health Information
Technology (ONCHIT) at the U.S. Department of Health and Human Services
(HHS) in 2004 to manage the "adoption of interconnected electronic health
records within 10 years" and charged HHS with developing the U.S. NHIN.[xxi]
Although the specifics for an American NHIN have not yet been finalized, it is
"envisioned as a public-private partnership of health information organizations
using common electronic formats, thereby enabling ease of access to EHRs
through any secure portal." [xxii]

Alan F. Westin has argued that Americans have been historically averse
to volunteering personal information about themselves to the federal government
for privacy concerns and that the public is hostile to, "combining information from
separate government agencies into central databanks" compared to the citizenry
of other nations. [xxiii] This belief is why the U.S. NHIN has been envisioned to be
a federated system of pointer databases maintained by trusted public and private
sector organizations rather than a single central repository.

The U.S. has historically been innovative in the use of technology to
combat industry and governmental needs but the country will not be an early
adopter of the technology of a NHIN as many other nations have already
established innovative solutions for their own needs. If the U.S. were to adopt

another nation's NHIN standards or the lessons learned from their

implementations, they must do so by considering the cultural, legal, and

regulatory differences that exist for these other nations when "balancing the

interests of privacy and confidentiality against the health care, economic, and

societal benefits of the NHIN" under a solely American perspective.[xxiv]   For

instance the cultures of the UK and Canada and their financial commitments to

Health IT have allowed them to be first movers in the adoption of EHRs on a

national perspective through a NHIN. Legally the United States does not have

an omnibus privacy law like in the EU or as centralized a framework as the

Canadian provincial model.[xxv] Instead the U.S. has a sectoral patchwork of laws

that cover civil liberties, health, finance, communications, and other industries via

specific legislation and regulations. Canada's privacy laws are the closest to the

U.S. because they are based mostly on provincial laws, similar to the state law

model that exists throughout America.

England's NHIN system is highly centralized and is "designed to serve the

National Health System, the publicly funded health care provider for over 50

million" British citizens, which equates to 88% of the net health care expenditures

in the UK.[xxvi] The information on individual demographic data and summary

health information per patient are stored on a central database, but the British

are not ignoring privacy as the summary report links to a separate locally

administered database for the patient's Detailed Care Records.[xxvii]

Canada's National Health Information Network, which has yet to be

officially launched, will have a different architectural model than the United

Kingdom centralized system. The Canada Health Infoway will be "formed by linking provincial or territorial electronic health information exchange systems…consisting of patient and provider registries as well as domain registries for prescription drug data, diagnostic imaging, and laboratory results." [xxviii] This too, like the provincial laws, would be closer to how the U.S. system would be designed as currently envisioned.

At the town hall meeting in Iowa, Clinton stated that Americans are going to have universal healthcare when she is elected, but clarified that her plan was to create "a health care system that provides quality affordable health care to every American" similar to the State of Massachusetts law that requires all state residents to have health insurance. [xxix] Mrs. Clinton made it clear that her plan was not to create a singular socialized medicine program that de-privatizes the industry. Britain and Canada are closer to this single government insurance resource and benefit regarding the logistics from having this vertical health care hierarchy but fail in promoting competition in the health insurance industry. These fundamental capitalist principles would never be ignored by the U.S.

The U.S. "has a mixture of public and private insurance" including, "the publicly funded Medicare and Medicaid insurance programs" which cover 25% of the U.S. population and account for 32% of health care expenditures, while "private health insurance, through employers or individually purchased, covers 58%." [xxx] The cost of health insurance has sky rocketed in the U.S. not due to the competition, but because of the mismanagement of the system without the needed investment in information technology. The financial industry and many

others have greatly benefited from adopting IT to improve efficiencies while the Health industry has rested on tradition. As Sen. Clinton mentioned in Iowa, now is the time to innovate.

The Clinton and Frist plan will leverage Medicare, Medicaid, the Veterans Administration (VA), Department of Defense (DoD), and the publicly funded healthcare of every federal civil servant and elected official in the U.S. Government – the largest single insurer of American lives in the United States – to begin this needed investment in Health IT.[xxxi] The Frist-Clinton and Bush NHINs are identical in design in calling for standardization across all federal government health care programs to allow for interoperability and voluntary enactment by private sector entities. If such a system were enacted today, through the lives just covered by the federal government the critical tipping point of fifteen-percent would have already been surpassed for the net health care industry, but trust in the system would still be low and the full value of a National Health Information Network would not be attained without private sector compliance.

Simon P. Cohn, M.D., M.P.H., Chairman of the National Committee on Vital Health Statistics, HHS, believes that "public support for the NHIN depends on public confidence and trust that personal health information is protected" and "any system of personal health information collection, storage, retrieval, use and dissemination requires the utmost trust of the public." [xxxii] Career civil servants, active military personnel in the DoD, retired personnel in the VA, and other government staff have a pre-existing trust relationship with the federal

government as their employer: thus their buy-in to the NHIN and an EHR system would be easier. But as 58% of the public are insured through private companies, their trust lies with Aetna, Blue Cross Blue Shield, Cigna, United Healthcare, et cetera and not with the government in the protection of their health information privacy; therefore the federal government should incentivize health insurance companies and other health organizations to implement the standards through tax credits.

Metcalfe's Law states that the usefulness of a network increases by the square of the different nodes, thus for the value of the NHIN to be fully realized it would need buy-in from all of the major private sector health care insurance companies, non-profit health clinics, and health organizations nationwide.[xxxiii] For the ability to reassure trust from the consumers and to optimize the value to its utmost potential, the U.S. National Health Information Network should be a federated system of every health care organization, no matter whether public, private, or non-profit. The maintenance of their databases should remain the organizations' responsibility but all information should be linked or attainable with proper authorization.

Although maintained locally, the networks' reach should be nationwide and administered by the Office of the National Coordinator for Health Information Technology (ONCHIT) at the U.S. Department of Health and Human Services (HHS). Their roles and responsibilities should only be as the owner of the network to guarantee upkeep that information is being inputted correctly and that

it continues to run, the policing of the network for abuse, and authorizing entities access to the network (See Appendix I).

Additionally, the responsibilities of the local parties should include the complete scope of moderating their own node to the network. For instance this would be analogous to a driver making sure his/her doors are locked when he/she parks the car in a public parking lot or privately ran parking garage in a shopping mall. The garage or parking lot may have employed security but their responsibility rests with the institution of the garage and not for each individual car. Each state's Attorney General or Chief Privacy Officer should maintain jurisdiction over the network in their region to adhere to compliance for the varied state privacy laws across the country.

Similar to the HIPAA Privacy Rule of 2003 HHS privacy standards adopted for the NHIN would not "affect state laws that provide additional privacy protections for patients" because the "confidentiality protections are cumulative" and the HHS "privacy rules will set a national 'floor' of privacy standards that protect all Americans." [xxxiv] The state privacy officers will maintain that these local laws are being adopted and followed. As insurance providers and health care organizations are opting into the network, individual consumers should also have the ability to opt-out of the network.

These opt-in and opt-out rules should bridge the NHIN to further adhere to the full scope of privacy best practices set forth in the 1973 Health Education and Welfare Advisory Committee on Automated Personal Data Systems principles, 1977 Privacy Protection Study Commission Fair Information Practices, and the

1980 OECD Guidelines on the Protection of Privacy and Transborder Flows of Personal Data.[xxxv] As technology in itself is not a silver bullet or panacea, these best practices will offer the policies and procedures needed to complement the technology and build trust in the NHIN.

Since medical history includes highly sensitive information, the security of the scope of use and authorization of consumers' EHRs is very important. Under the Fair Information Practices, an EMT or another first responder bringing a man with a broken arm to the hospital would not need any access to the man's psychological records and/or know if he had a history of substance abuse.[xxxvi] The limited use and purpose specification principles should also restrict abuses of the network for secondary or non-health related reasons pertaining to the individual. For instance police, DHS, or the FBI should not have the ability to "phish" or "pharm" the system for criminals such as narcotics abusers nor should insurance companies abuse the system by researching information to drop their higher-risk clients with chronic diseases or who may be predisposed to such a disease by their genetic makeup because those actions all hurt the consumer trust for a NHIN and would continue to encourage citizens to lie or be selective in what they discuss/volunteer to doctors and health agents.[xxxvii]

Access to the NHIN should also follow industry best practices. ChoicePoint General Counsel and Chief Privacy Officer Carol DiBattiste referenced in a discussion at Georgetown University that the most sensitive data that the company retains is truncated and masked; and before a customer is authorized to access the database they must pass a test to validate their claim of

who they are portraying to be online.[xxxviii] And to combat abuse at the local network level, if the customer fails the test twice consecutively, they are locked out of the system.[xxxix] The Office of the National Coordinator for Health Information Technology (ONCHIT) at HHS as the owner and administrator of the proposed NHIN should follow a similar procedure before authorizing a hospital, clinic, emergency responder, or health care organization access to the network.

Once credentialed and authorized to access the system, any admittance to an individual's personal health record should automatically leave a breadcrumb and time stamp that is inserted to the record so the ONCHIT or the individual themselves can police the EHR for abuse. As the in-efficiency of valid access – in addition to the trust of the network – could dissuade authorized uses for emergency personnel and hospitals a biometric can be used for the credentialing to save time in an emergency response without the need to take a test or input a custom username, password, and pin for access: like at a bank ATM machine.

The NHIN should be accessible via any connection to the Internet but should be heavily secured and protected behind a firewall that requires unique access protocols, such as the username, password, and pin combination or a biometric. If the network was IP accessible, mobile device applications could be created and other networked Health IT hardware devices – such as blood pressure monitors that could write to your account – can add additional statistics to record keeping while removing the human element for increased privacy and reduced opportunity for human error, such as typographical or memory related.

Today only one-percent of all medication errors are being caught by the current health care system, which causes the equivalent number of annual fatalities as a full 747 airplane crashing every day.[xl] The federal government should make available free open source software to all private sector parties, similar to the current program they are running with the Veterans Administration VistA program for this increased functionality, while maintaining the standardization and interoperability.[xli]

VistA could be used as the backbone of the U.S. NHIN or at least the first phase of the deployment of a national system. The Veterans Administration mandated that all of its 154 hospitals and 875 clinics nationwide move to a paper-less interconnected EHR system through VistA authorization and it has improved the accuracy of prescriptions being filled at the VA to 99.997 percent.[xlii] This success is far above the national average where three to eight percent are filled erroneously due to human errors related to typographical errors, illegibly hand written notes, memory lapses, or simple mis-rationing by a pharmacist.[xliii]

VA serves 5.4 million patients and has already transitioned to a 21st century medical establishment with this single program. This allows them to focus less on administrative problems and focus their time and money more effectively on operational issues. As the rollout for the NHIN is being benchmarked for 2004 to 2014, the federal government must not create a new business plan but link together the successes of VistA and the many other interagency programs government wide. They must adopt the lessons learned and successes of VistA, Canada, and Britain to create a tool that allows their

legacy systems to interact with the NHIN or they will not obtain the trust and buy-in from users that will make the tool a success.

In addition to the technical design of the NHIN, such as making it compatible with older networks, HHS must educate their users and the public about the benefits of the tool and show how those benefits outweigh any perceived or legitimate security risks that the consumers may have with their private medical information being digitized and accessible via a networked Internet based tool. Unlike the VA that mandated the users' compliance, HHS must allow opt-outs for consumers and leave it voluntary for private entities to join and/or leave the network; but at a minimum the private sector should be highly encouraged – through tax credits or other financial means – to adopt the standards for data retention to increase the potential value of the data under Metcalfe's Law.

If private insurance brokers implement these standards but do not opt to allowing their databases to be linked to the NHIN, it will at least give the consumer agency for the portability or transferability of their personal EHR once/if they switch insurance providers. As this data is being transferred to and from the NHIN, the threat of a breach is credible—therefore all data in the NHIN must be protected while in transmission; while stored in the databases; and while queried or saved in a computer's cache.[xliv] This data should only be accessible when an authorized user accesses the data and protections must be in place for the exporting, printing, or saving of any dataset for use outside of the network. Policing any abuses must be one of the primary roles of the Office of the National

Coordinator for Health Information Technology (ONCHIT) at HHS; as well as equally shared with the State Attorney Generals, state Chief Privacy Officers, and local network private and public sector privacy officers. Without these policing mechanisms and layered safeguards being instituted, there would be low perceived safety of the protection of sensitive privacy information from consumers thus a limited trust and limited use of the tool. Criminalizing abuses with strict penalty codes must also be grouped into the policing mechanisms on a national and state-by-state basis to dissuade malicious actors from attempting to abuse the tool.

Data retention for the NHIN should include all medical history from birth to death of citizens but historical medical information must be partitioned by an appropriate period of time – whether annually, by decade, or another value agreed upon by all stakeholders. By partitioning the data by a timely variable, the usefulness of the data is increased if a historical account of a patient is necessary, while combating the Law of Diminishing Returns for non-historical activities.[xlv] Kryder's Law and Moore's Law have allowed the cost for storage of data to be a non-factor for retention as well as the retrieval speeds to be at an acceptable level for the necessary emergency uses of a NHIN and EHR system.[xlvi] When Gerald Ford studied computerized data retention writ-large in the 1970s or even when Hilary Clinton spearheaded the White House Task Force on Health Reform in the early 1990s, technology could not have absorbed the bandwidth necessary to run the system and the physical hard-disk space was cost prohibitive for the scale needed to run an effective NHIN but today the

technology, encryption algorithms, compression formats, software tools, lowered costs, and bandwidth make it feasible.

After the phased rollout in 2014 of the U.S. National Health Information Network, HHS should partner with the World Health Organization (WHO) to promote the deployment of interoperable NHINs abroad. As privacy laws vary around the world – especially in regard to the transmission of data across borders – this creates an additional privacy risk, but an international NHIN could significantly increase the ability for researchers at the WHO to study health trends and allow doctors to treat patients in a globalized world with greater ease while exponentially optimizing Metcalfe's Law. And as many developing nations do not have adequate health care facilities or a workforce, the deployment of health IT tools could allow them access to intellectual capital abroad. The WHO and HHS should continue to adhere strictly to the 1980 OECD Guidelines on the Protection of Privacy and Transborder Flows of Personal Data when linking nationalized NHINs.

Information Technology has been utilized in many industries to revolutionize day-to-day practices and Health IT can do the same to the dying healthcare industry. Thomas Jefferson wrote in the Declaration of Independence that every man, woman, or child should have the unalienable rights of, "life, liberty, and the pursuit of happiness," but currently 47 million Americans are being denied their right to "life" because they are uninsured. Former U.S. Senator representing the State of New Jersey and 2000 Presidential hopeful Bill Bradley calls this, "a betrayal of the Founders' promise." [xlvii] Ironically,

Jefferson's famous quote comes from the context of John Locke's *Second Treatise of Government* (1690) which originally included health care.[xlviii] The English philosopher originally stated that, "no one ought to harm another in his life, health, liberty, or possessions." [xlix] Without offering insurance to these citizens, the U.S. government is harming their claims to health, life, and happiness.

And like these unalienable rights, Massachusetts' former-governor and 2008 Republican Presidential hopeful Mitt Romney, who like Hillary Clinton is the leading nominee of his party, feels that all U.S. residents should be required to have health insurance…but not as an unalienable right but as an "individual mandate." [l] Employers are tasked with more responsibility under the Massachusetts plan and the state government subsidizes the residents that do not receive employee funded insurance and who cannot afford to purchase private insurance on their own.[li] Whether it be the first female President in Hilary Rodham Clinton continuing the mission of her husband left in 1993-1994, the first Mormon President in Mitt Romney broadening his universal health care program from Massachusetts to apply to all states, the first Black-American President in Barrack Obama spreading new ideas as a fresh face to politics, or any of the other leading candidates they will need to breadth life into the dying U.S. health care system in 2008 once they are elected.

This new leader has the opportunity to offer CPR to the health care industry by creating the first National Health Information Network in the United States. With the deployment of a trusted NHIN that benefits from a vast public

and private sector acceptance, like the Veterans Administration ability to focus on operational issues today, the U.S. government can realign its spending and time management and focus more on operational issues facing the country such as the growing national debt, the wars in Iraq and Afghanistan, the inabilities of our public education system to properly train America's youth, and global warming. Individuals will be able to save more as the price of health care will go down and could put that money back into the economy, thus creating more jobs. And like the growing problems with social security, this epidemic of health spending must be addressed before the baby boomers retire in the coming years.

A well managed NHIN that protects privacy and builds consumer trust will not just be a step in the right direction to confront these problems but a giant leap forward. A leap passed the partisanship and lobbying might of 1993 and 1994 and a positive move towards what is best for the 47 million American men, women, and children and the millions more that subsidize their being uninsured when they visit the hospital for an emergency. When one of the richest countries in the world that prides itself on capitalism and democratization spends only slightly more than the price of a USPS stamp on Health IT expenditures per capita, in an economy of the Information Age, its citizens suffer. Now is the time for a change.
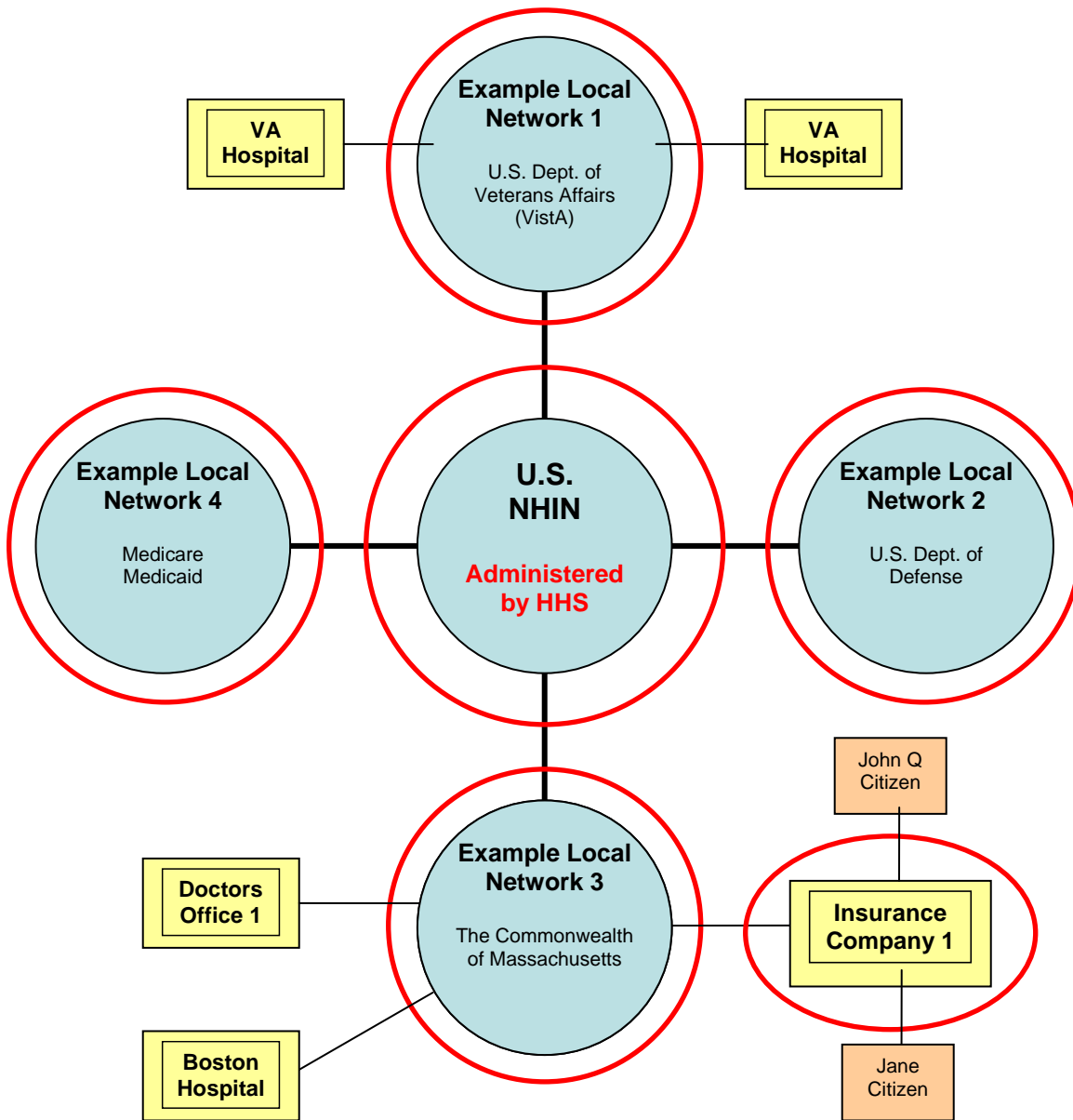
Works Cited

Anderson, Gerald F, et al. "Health Care Spending and Use of Information Technology in OECD Countries." Heath Affairs: The Policy Journal of the Health Sphere. Journal 25, 3. 2006.

Arnst, Catherine. "The Best Medical Care in the U.S.: How Veterans Affairs Transformed Itself – and What it Means for the Rest of Us." BusinessWeek. 17 July 2006.

Bernstein, Maya. Interview with Jason Langsner. Phone Conversation. 6 April 2007.

Bradley, Bill. The New American Story. New York: Random House, 2007.

Cohn, Simon P. "Letter to the Secretary; Recommendations regarding Privacy and Confidentiality in the National Health Information Network." National Committee on Vital and Health Statistics. 22 June 2006.

DiBattiste, Carol. Address. Georgetown University, Washington, DC. 3 April 2007.

DiBattiste, Carol. Email Correspondence with Jason Langsner. 6 April 2007.

"Frist, Clinton Introduce Health Technology to Enhance Quality Act of 2005." U.S. Senator Hillary Rodham Clinton Website. 16 June 2005. <http://www.clinton.senate.gov/news/statements/details.cfm?id=239875>.

"Health Insurance Portability and Accountability Act of 1996: Public Law 104-191." The 104th U.S. Congress. 21 August 1996. <http://aspe.hhs.gov/admnsimp/pl104191.htm>.

Hillestad, Richard, et al. "Can Electronic Medical Record Systems Transform Health Care? Potential Health Benefits, Savings, and Costs." Health Affairs: The Journal of the Health Sphere. Journal 24, no. 5, 2005.

Hughes, Trevor. Address by the Executive Director of the International Association of Privacy Professionals. Georgetown University, Washington, DC. 10 April 2007.

"Legislative Tracking." Massachusetts Health Data Consortium. 30 August 2006. <http://www.mahealthdata.org/data/library/legislative.html>.

Poore, Ray. Interview by Jason Langsner with Ray Poore, Assistant Chief Freedom of Information Officer, Office of eGovernment and Records Management, U.S. Department of Veterans Affairs. IAPP/TRUSTe KnowledgeNet Symposium. Wiley Rein LLP, Washington, DC. 29 March 2007.

Pritts, Joy and Kathleen Connor. "The Implementation of E-consent Mechanisms in Three Countries: Canada, England, and the Netherlands." U.S. Department of Health and Human Services. 16 February 200. pgs 1-8.

"Protecting the Privacy of Patients' Health Information." U.S. Department of Health and Human Services. 14 April 2003. <http://www.hhs.gov/news/facts/privacy.html>.

Rothstein, Mark A. and Meghan K. Talbott. "Compelled Disclosure of Health Information: Protecting Against the Greatest Potential Threat to Privacy." Journal of the American Medical Association. Volume 295, No. 24. 28 June 2006.

"S. 1626: The Health Technology to Enhance Quality Act of 2005 – The Health TEQ Act." U.S. Senator Hillary Rodham Clinton Website. 16 June 2005. <http://www.clinton.senate.gov/documents/S1262.pdf>.

Schwartz, Ari. "Testimony of Ari Schwartz, Policy Analyst, The Center for Democracy and Technology." U.S. House Committee on Government Reform, Subcommittee on Government Management, Information and Technology. 12 April 2002.

"Senator Hillary Clinton Answers Iowans; Questions." Good Morning America. Anchor Robin Roberts. Produced Town Hall Meeting in Iowa. ABC News. Aired 26 March 2007.

Symonds, William C. "In Massachusetts, Health Care for All?" BusinessWeek Online. 4 April 2006 <http://www.businessweek.com/investor/content/apr2006/pi20060404_152 510.htm>.

"United States Department of Health and Human Services News 1993 – A Year of Accomplishments." U.S. Department of Health and Human Services. 22 December 1993 <http://www.hhs.gov/news/press/pre1995pres/931222.txt>.

VistA-Office EHR." Office of the National Coordinator for Health Information Technology (ONC): U.S. Department of Health and Human Services. 23 September 2005. <http://www.hhs.gov/healthit/VAvista.html>.

Westin, Alan F. "Social and Political Dimensions of Privacy." Journal of Social Sciences, Volume 59, No. 2, 2003.

Appendix I

A Schematic Diagram of the Proposed
U.S. National Health Information Network (NHIN)

VA Hospital

Example Local Network 1

U.S. Dept. of Veterans Affairs (VistA)

VA Hospital

Example Local Network 4

Medicare Medicaid

U.S. NHIN

Administered by HHS

Example Local Network 2

U.S. Dept. of Defense

John Q Citizen

Doctors Office 1

Example Local Network 3

The Commonwealth of Massachusetts

Insurance Company 1

Boston Hospital

Jane Citizen

Key

⬤ = Security Ring / Firewall around the Local and National Networks

⬤ = A Network on the NHIN

▭ = A Node on the Local Network

▭ = An individual node on the Local Node of a Network

Endnotes

[i] "Senator Hillary Clinton Answers Iowans; Questions." <u>Good Morning America</u>. Anchor Robin Roberts. Produced Town Hall Meeting in Iowa. ABC News. Aired 26 March 2007. Transcript available on <http://abcnews.go.com/GMA/story?id=2981027&page=1&CMP=OTC-RSSFeeds0312>.

[ii] Bradley, Bill. <u>The New American Story</u>. New York: Random House, 2007. pg. 137.

[iii] Bradley, pg. 142.

[iv] "United States Department of Health and Human Services News 1993 – A Year of Accomplishments." <u>U.S. Department of Health and Human Services</u>. 22 December 1993 <http://www.hhs.gov/news/press/pre1995pres/931222.txt>.

[v] "Senator Hillary Clinton Answers Iowans; Questions."

[vi] "Health Insurance Portability and Accountability Act of 1996: Public Law 104-191." <u>The 104th U.S. Congress</u>. 21 August 1996. <http://aspe.hhs.gov/admnsimp/pl104191.htm>.

[vii] Westin, Alan F. "Social and Political Dimensions of Privacy." Journal of Social Sciences, Volume 59, No. 2, 2003.

[viii] "Senator Hillary Clinton Answers Iowans; Questions."

[ix] Anderson, Gerald F, et al. "Health Care Spending and Use of Information Technology in OECD Countries." <u>Heath Affairs: The Policy Journal of the Health Sphere</u>. Journal 25, 3. 2006.

[x] Bradley, pg. 137.

[xi] Bradley, pg. 140.

[xii] Anderson.

[xiii] Ibid.

[xiv] "Frist, Clinton Introduce Health Technology to Enhance Quality Act of 2005." <u>U.S. Senator Hillary Rodham Clinton Website</u>. 16 June 2005. <http://www.clinton.senate.gov/news/statements/details.cfm?id=239875>.

[xv] "Legislative Tracking." <u>Massachusetts Health Data Consortium</u>. 30 August 2006. <http://www.mahealthdata.org/data/library/legislative.html>.

These other bills include: S. 3678 - Pandemic and All-Hazards Preparedness Act.; S. 3739 - Consortium on the Impact of Technology in Aging Health Services Act of 2006 (also introduced in House as H.R. 5906); H.R. 5864 - Health Partnership Through Creative Federalism Act.; S. 1223 - Information Technology for HealthCare Quality Act; S. 1227 - Health Information Technology Act of 2005; S. 1355 - Better Healthcare Through Information Technology Act; S. 1356 - Medicare Value Purchasing Act of 2005; S. 1418 - Wired for Health Care Quality Act; S. 1789 - Personal Data Privacy and Security Act of 2005; H.R. 2234 - 21st Century Health Information Act of 2005; H.R. 3205 - Patient Safety & Quality Improvement Act ; H.R. 4157 - Health Information Technology Promotion Act of 2005; H.R. 4641 - Assisting Doctors to Obtain Proficient and Transmissible Health Information Technology (ADOPT HIT) Act of 2005

[xvi] Hillestad, Richard, et al. "Can Electronic Medical Record Systems Transform Health Care? Potential Health Benefits, Savings, and Costs." <u>Health Affairs: The Journal of the Health Sphere</u>. Journal 24, no. 5, 2005.

By "anonymous" data, the information pertaining to a unique identifier – such as the name or social security number – to an individual is removed.

[xvii] Ibid.

[xviii] Ibid.

[xix] Bradley, pg. 135.

[xx] "S. 1626: The Health Technology to Enhance Quality Act of 2005 – The Health TEQ Act." <u>U.S. Senator Hillary Rodham Clinton Website</u>. 16 June 2005. <http://www.clinton.senate.gov/documents/S1262.pdf>.

[xxi] Rothstein, Mark A. and Meghan K. Talbott. "Compelled Disclosure of Health Information: Protecting Against the Greatest Potential Threat to Privacy." <u>Journal of the American Medical Association</u>. Volume 295, No. 24. 28 June 2006.

xxii Ibid, pg. 2882.

xxiii Westin, p. 439.

xxiv Cohn, Simon P. "Letter to the Secretary; Recommendations regarding Privacy and Confidentiality in the National Health Information Network." National Committee on Vital and Health Statistics. 22 June 2006.

xxv Hillestad.

xxvi Pritts, Joy and Kathleen Connor. "The Implementation of E-consent Mechanisms in Three Countries: Canada, England, and the Netherlands." U.S. Department of Health and Human Services. 16 February 200. pgs 1-8.

xxvii Ibid.

xxviii Ibid.

xxix "Senator Hillary Clinton Answers Iowans; Questions." and Symonds, William C. "In Massachusetts, Health Care for All?" BusinessWeek Online. 4 April 2006 <http://www.businessweek.com/investor/content/apr2006/pi20060404_152510.htm>.

xxx Pritts, p. 2.

xxxi "Senator Hillary Clinton Answers Iowans; Questions."

xxxii Cohn.

xxxiii Hughes, Trevor. Address by the Executive Director of the International Association of Privacy Professionals. Georgetown University, Washington, DC. 10 April 2007.

xxxiv "Protecting the Privacy of Patients' Health Information." U.S. Department of Health and Human Services. 14 April 2003. <http://www.hhs.gov/news/facts/privacy.html>.

xxxv Schwartz, Ari. "Testimony of Ari Schwartz, Policy Analyst, The Center for Democracy and Technology." U.S. House Committee on Government Reform, Subcommittee on Government Management, Information and Technology. 12 April 2002.

xxxvi Bernstein, Maya. Interview with Jason Langsner. Phone Conversation. 6 April 2007.

xxxvii Ibid.

xxxviii DiBattiste, Carol. Address. Georgetown University, Washington, DC. 3 April 2007.

xxxix DiBattiste, Carol. Email Correspondence with Jason Langsner. 6 April 2007.

xl Bradley, pg. 146.

xli "VistA-Office EHR." Office of the National Coordinator for Health Information Technology (ONC): U.S. Department of Health and Human Services. 23 September 2005. <http://www.hhs.gov/healthit/VAvista.html>.

xlii Arnst, Catherine. "The Best Medical Care in the U.S.: How Veterans Affairs Transformed Itself – and What it Means for the Rest of Us." BusinessWeek. 17 July 2006.

xliii Ibid.

xliv Poore, Ray. Interview by Jason Langsner with Ray Poore, Assistant Chief Freedom of Information Officer, Office of eGovernment and Records Management, U.S. Department of Veterans Affairs. IAPP/TRUSTe KnowledgeNet Symposium. Wiley Rein LLP, Washington, DC. 29 March 2007.

xlv Bernstein.

xlvi Hughes.

xlvii Bradley, pg. 137.

xlviii Locke, John. "The Second Treatise of Civil Liberties." Originally published 1690: London, England. Republished by Barnes & Noble, 2004. Available in the commons at: <http://books.google.com/books?id=oOjoGkmMWUMC&dq=Second+Treatise+on+Government &psp=1>.

xlix Ibid.

l Seymonds.

li Ibid.