Social Security Administration (SSA)
Specialized Advisory and Assistance Services (SAAS)

Using the Nationwide Health Information Network to Deliver Value to Disability Claimants:

A Case Study of Social Security Administration and MedVirginia Use of MEGAHIT for Disability Determination

Sue S. Feldman, RN, MEd
Thomas A. Horan, PhD

Kay Center for E-Health Research
Claremont Graduate University

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Executive Summary

Health Information Technology (Health IT) is widely considered to be one of the key elements for improving the efficiency and quality of healthcare. Until recently, the uses and benefits of Health IT were given little consideration outside of the clinical environment. As the nation's primary disability benefit provider, the Social Security Administration (SSA) is among the largest users of medical record information in the United States, specifically for disability benefit determination. As such, SSA has turned to Health IT solutions to streamline processes and expedite information delivery of claimant information and medical records for disability determination.

In August 2008, SSA engaged in a successful proof of concept with Beth Israel Deaconess Medical Center (BIDMC) to send an authorized request for and receipt of patient health information using the Medical Evidence Gathering and Analysis through Health IT (MEGAHIT) application. This authorized request and receipt, which used Health IT industry standards for healthcare information exchange, was across a secure point-to-point network, and therefore had limits in terms of scalability for multiple providers and nationwide deployment. Consequently, the next important step was demonstration of a scalable solution. This was subsequently achieved when SSA (a public agency) and MedVirginia (a private Health Information Exchange (HIE)) collaborated to use the Nationwide Health Information Network (NHIN) as a secure and interoperable transport environment for patient information.

This case study reports on the advancement of the authorized request for and receipt of patient health information across the NHIN. This limited production effort is distinctive not only for SSA, but represents the very first production exchange of health information across the NHIN. SSA and MedVirginia "went live"—that is, requesting and receiving actual patient information across the NHIN—on February 28, 2009, and the production effort remains operational. The case study was conducted from June 2009 to November 2009 and findings were primarily derived from interviews with 43 participants from a variety of organizations. Findings are reported across technical, organizational, and governance domains in terms of challenges, successes, and considerations for moving forward. Although several generic matters are discussed, the focus is primarily on the nuances of using the NHIN as a secure transport mechanism for authorized patient information.

Achieving interoperability between MedVirginia's clinical repository system and their proprietary gateway and identifying an authorization standard for the SSA Authorization to Disclose Information (Form 827) were two major technical challenges noted by participants. Prior to going "live," the MedVirginia team put forth a great deal of effort to ensure the interoperability between their clinical repository system and their gateway. Several months after they were in production, MedVirginia changed from their initial proprietary gateway to the newly released Federal Health Architecture (FHA) developed open source CONNECT gateway. This change was due in part to evolving Health IT standards and MedVirginia's belief that the gateway change would prove to be a more sustainable model for the future. The second major challenge involved identifying an existing technical standard that would accommodate both the placement of the authorization and the image of the authorization. In terms of technical success, the authorized medical evidence request and receipt took approximately 2 minutes, including Continuity of Care Document (CCD) rendering, resulting in a mean case processing time savings of 42% as compared to the Virginia Disability Determination Service (DDS) state average. Moving forward, as organizations seek to exchange health information via the NHIN, they may benefit from using the CONNECT gateway which offers the core interoperability standards, especially as Health IT standards continue to evolve.

Organizationally, the production effort required collaboration among multiple stakeholders; SSA was seeking claimant health information, MedVirginia was providing patient health information, and other parties, such as the Office of the National Coordinator (ONC) facilitated the transporting of patient information across the NHIN. Within this multiorganizational collaboration, two main challenges emerged: perceived value proposition variances and communication. In terms of value proposition, those interviewed noted that each organization had its own motivations for participation. In terms of communication, the number of organizations involved meant a greater frequency of meetings and a larger number of meeting participants, which inherently created complexities. Organizational successes occurred because of leadership and collaboration both vertically within each organization and horizontally among organizations. These elements were viewed as important in maintaining a sense of excitement and vision to stay the course. Moving forward, resolving value proposition variances will be important. While the value to SSA may be clear for the expeditious authorized request for and receipt of claimant health information, it may be less transparent to providers as to how their participation in such an endeavor will benefit their organizations, especially from a fiscal perspective.

Governance includes oversight, standardized policies and procedures, and mechanisms of assurance. According to those actively involved, this limited production effort was able to tolerate and even benefit from an “ad-hoc” multiparty governance structure. However, considerations surrounding a formalized governance structure and issues of privacy and security emerged as main governance challenges. Privacy and security are also critical areas of focus as the NHIN matures and becomes more broadly used. This will involve reconciliation of state and federal policies and consumer options for health data exchange.

The value provided to disability claimants was the focus of the success metrics across the three domains: technical, organizational, and governance. As such, technical metrics for faster authorized request, receipt, and preliminary analysis of medical evidence hold the promise for more expeditious disability determinations. Organizational metrics of success for the providers who submit medical evidence across the NHIN could lead to increased access to and utilization of healthcare services for persons with disabilities and subsequent better health outcomes. Additionally, care compensation is perceived to be an important and measurable provider value proposition. From a governance perspective, a measure of success will be an increase in the number of NHIN participants. Formal governance structures would facilitate organized and streamlined participation.

Utilizing the NHIN as a transport mechanism to send an authorized request (with a signed Form 827) and receive medical evidence for disability determination required numerous collaborative efforts across multiple organizations. Challenges exist in health information exchange in general (e.g. Continuity of Care Document (CCD)creation and the various levels of provider technical readiness), and the transmission of health information is further complicated when using the NHIN (e.g. identification of providers, privacy and security). The focused efforts and collaboration of SSA, MedVirginia, and the Office of the National Coordinator for Health IT (ONC) resulted in a technical, organizational, and governance success. This success brings to light the significance of and potential for requesting and receiving patient health information across the NHIN.

The technical, organizational, and governance challenges, successes, and considerations for moving forward that are documented in this study will serve to inform interested stakeholders as SSA continues to engage additional providers for the collection of health information via the NHIN.

Background

The seminal report, *Crossing the Quality Chasm*, discussed the potential value of Health Information Technology (Health IT) in saving lives and healthcare dollars [1]. In this report, those savings were characterized within a clinical care environment; a discussion of the benefits of Health IT for alternative uses such as benefit determination (disability or otherwise) was not addressed. The Social Security Administration (SSA), as a key provider of disability benefits, is a major user of healthcare data in the United States (U.S.) and spends over $500 million annually to collect medical information for the more than 3 million initial disability applicants it receives each year. SSA has articulated a vision to use Health IT solutions to improve efficiencies and reduce the amount of time claimants wait for a disability determination. For some claimants, attaining SSA disability benefits can facilitate access to healthcare coverage (Medicare or Medicaid)[1] and to provider services. These benefits and services can translate into avoidance of financial burden and improved health outcomes for the claimants and into healthcare savings for providers.

This case study is an analysis of the collaborative effort among SSA, the MedVirginia Health Information Exchange (HIE), and the Nationwide Health Information Network (NHIN) to use Health IT for the authorized request (with a signed Form 827), receipt, and transmission of patient health information for disability determination. This limited production effort[2] is significant and distinctive because it is the first time "live" health information was transmitted via the NHIN as the secure and interoperable transport mechanism. This information request and receipt was accomplished using published standards and protocols and employed innovative open source software.[3]

Social Security Administration

While SSA's disability determination process is primarily electronic, the medical evidence development process remains largely paper-based.[4] Disability applications begin when a claim is filed with SSA (internet, telephone, in person) at a field office. The field office then sends a signed Form 827 to the state Disability Determination Services (DDS) office where an authorized request to the claimant's healthcare provider(s) for supporting documentation (medical evidence) is generated. The subsequently collected medical evidence is used to make a decision about the merits of the claim. At this point, an arduous process begins, as most healthcare providers utilize paper-based medical records or use highly customized or proprietary electronic health record (EHR) systems that may not conform to current industry healthcare interoperability standards. Consequently, what typically unfolds is a set of requests and rerequests for medical evidence. Unfortunately, many of the responses are incomplete, some are massive, and many requests remain unanswered resulting in delays and increased disability determination costs.

As a leader in the use of information systems to streamline business processes, SSA has made a commitment to use Health IT to reduce the amount of time a claimant must wait for a disability

[1] In many states, Supplemental Security Income (SSI) eligibility results in Medicaid eligibility.
[2] Limited production refers to the limited number of participants (as in one HIE), not a limited number of features provided.
[3] Open Source software refers to technology neutral applications that are transparent as far as source code, accessibility, and modifications. Traditionally, Open Source applications are freely distributed without discrimination [2].
[4] When SSA collects medical records, those records become medical evidence.

determination [3]. While SSA has several electronic means by which medical evidence can be submitted,[5] one notable advancement is the development of the MEGAHIT (Medical Evidence Gathering and Analysis though Health Information Technology)[6] application. A previous point-to-point proof of concept (SSA-BIDMC project) yielded a mean case processing time[7] savings of 41% as compared to the national average.[8] With these results, SSA sought to expand their efforts toward multi-provider connections and data exchange using the NHIN as the transmission vehicle. These efforts seek to increase the amount of standardized medical evidence received and augment preliminary analysis, thus accelerating the disability determination process. Through these collective actions, SSA seeks to decrease the amount of time a claimant must wait for a disability determination.

MedVirginia

MedVirginia, Virginia's Regional Health Information Organization (RHIO), is an HIE[9] in the Richmond, Virginia area, which began in 2001 with a vision to create communities of care and become the most health data connected community in the nation. By 2005, utilizing the Internet, MedVirginia launched a Health Insurance Portability and Accountability Act (HIPAA)[10] compliant portal giving clinicians access to lab, pharmacy, and other patient health information at the point of care. MedVirginia houses over 600,000 patient charts and services over 300 physicians and six hospitals. Four of these hospitals were involved in the live data exchange with SSA at the time of this case study.

In 2007, MedVirginia was selected as one of the original NHIN Trial Implementation participants and quickly began building cooperative relationships for the exchange of test data across the NHIN. In December 2008, MedVirginia and SSA entered into an arrangement to pursue transmission of live health information across the NHIN for disability determination. On February 28, 2009 MedVirginia and SSA went live, using the NHIN, with the first transmission of live patient health information for disability determination.

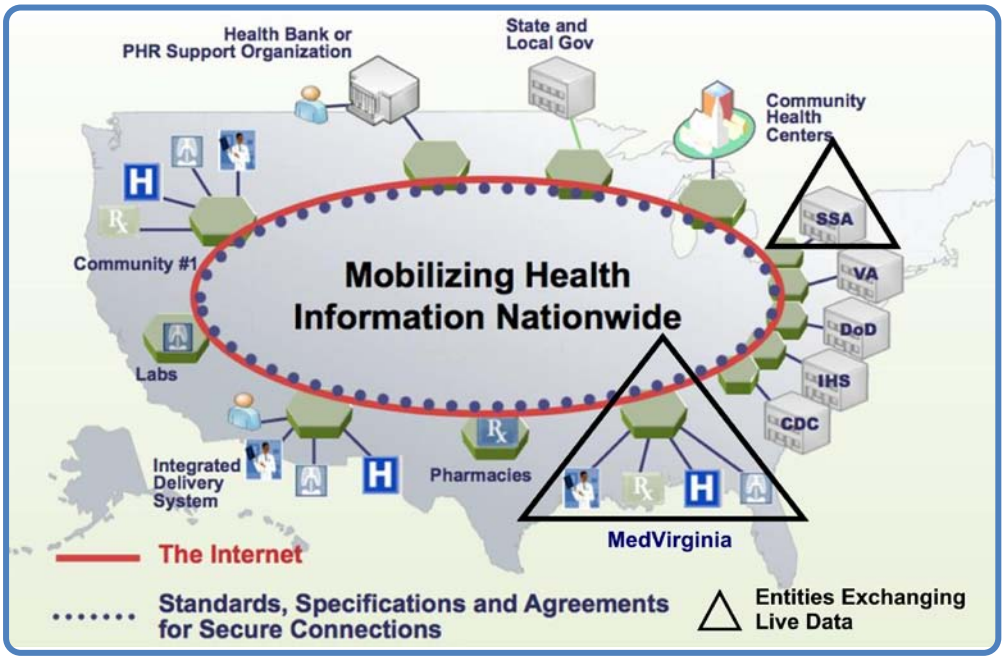
Nationwide Health Information Network (NHIN)

The NHIN, which uses the technology of the Internet, was initiated in 2004 by the United States Department of Health and Human Services (HHS) Office of the National Coordinator (ONC) as a means to facilitate the secure and interoperable exchange of health information among providers and HIEs [4]. By October 2007, Federal agencies joined the NHIN forming a Cooperative with

[5] Electronic Records Express (ERE) is an example of other methods developed by SSA allowing electronic submission of medical evidence. However, all previous methods do not produce standardized documents nor allow for analysis by an application such as MEGAHIT.
[6] MEGAHIT is a data transmission and analysis application encompassing the authorized release, collection, and analysis (using business rules) of medical data for disability determination. As such the SSA IT system "contacts" another system (provider) requesting medical evidence for a claimant, whereby the provider generates Medical Evidence Record (MER) that is transmitted to and reviewed by SSA for a disability determination.
[7] Mean case processing time measures the time the case is in the DDS office only, it does not include any time in the field office or quality review component, if any.
[8] Analysis limited to MEGAHIT use in the Boston area only with Beth Israel Deaconess Medical Center. The results of this study do not necessarily imply those same results are possible in a nationwide roll-out, but instead illustrate the potential for time savings.
[9] In this instance, MedVirginia is an HIE with a data repository collecting and housing multiple pieces of clinical data from disparate sources (i.e. lab, pharmacy, providers, etc.).
[10] http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html

participating HIEs with the goal of exchanging health information across this network of networks. Since that time, others have joined the Cooperative with successful sharing of test data. Figure 1 graphically represents the NHIN and various provider relationships.

Figure 1. Graphic Representation of the SSA-MedVirginia-NHIN relationship
(Source: Modified from SSA)



ONC has many evolving responsibilities related to the NHIN, including leveraging current Healthcare Information Technology Standards Panel (HITSP) specifications for interoperability and content standards.[11] FHA, an entity of HHS, works closely with ONC to use standards to foster interoperable health information exchange.[12] Additionally, FHA oversees the development and implementation of the open source CONNECT[13] solution which facilitates provider connections for the secure and interoperable transport of data.

SSA-MedVirginia-NHIN Project

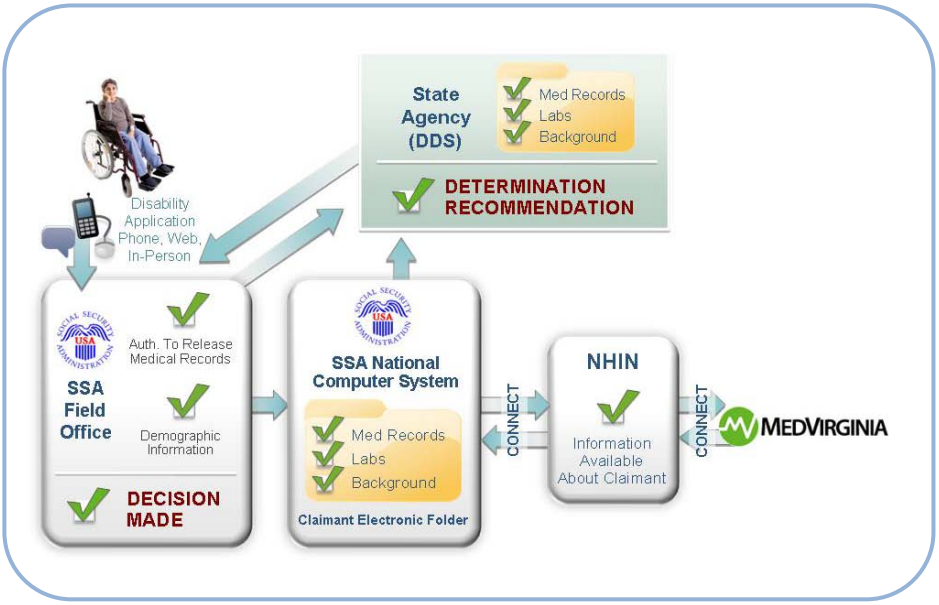
This collaborative project was inspired by a shared vision to expedite and improve disability claims in the United States by implementing authorized request for and receipt of claimant health information across the NHIN. Throughout the project, technical, organizational, and governance challenges were encountered and achievements were attained.

Using the NHIN as the transport mechanism, Figure 2 illustrates the information flows established during this project. The flow begins with the application for disability benefits. When the applicant's treating source(s) is identified as a MEGAHIT participating provider (such as MedVirginia), SSA's MEGAHIT application automatically initiates an authorized release of

[11] http://www.hitsp.org/
[12] http://www.hhs.gov/fedhealtharch/
[13] The CONNECT gateway is the federally-built open source solution that can be used to connect providers to the NHIN [4].

information request to the treating source along with a signed Form 827. Following this request, the patient health information moves from the provider through the NHIN to SSA's National Computer System. SSA's MEGAHIT application applies business rules[14] to the incoming information and performs preliminary disability allegation analysis and subsequent DDS examiner guidance. Additionally, SSA's system converts this information into a SSA-standardized human readable document, and places this information into the claimant's electronic folder for access by a DDS examiner who further evaluates the claim for disability determination.

Figure 2. Information flow from application to provider and back to DDS examiners
(source: SSA)



The goal of this limited production project was to use the NHIN for secure and interoperable transmission of patient health information for disability determination. In so doing, this project represented the coming together of SSA and MedVirginia in a unique authorized request for and receipt of live health information over the NHIN. This case study documents the challenges and successes of this effort. Additionally, it illuminates some of the considerations for moving forward using the NHIN as the transport vehicle in the submission of electronic medical evidence to SSA from an HIE or other such provider of medical evidence.

Methodology

The project utilized case study design to understand challenges, successes, and considerations moving forward across technical, organizational, and governance domains. Within each domain, exploration of multiple dimensions ensured sufficient depth and breadth in the case study information gathering and analysis. Metrics of success within and across the domains were also examined. Figure 3 illustrates the case study methodology and Figure 4 illustrates the domains and dimensions within the framework.

[14] Business rules are a predictable and traceable process of matching newly acquired health data against predetermined criteria (a set of listings) to generate new knowledge or information [5].

Figure 3. Case study methodology

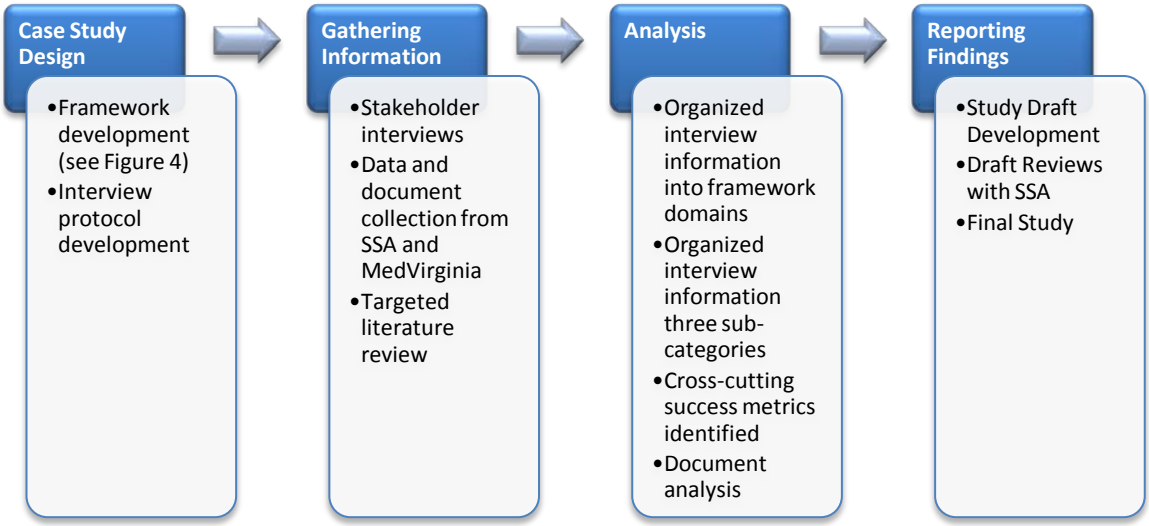


Figure 4. Framework domains and dimensions

The framework was used to gain an understanding of the collaborative process used in this project. Perspectives of the stakeholder groups were explored using semi-structured single and focus group interviews. Interviewees included officials and staff from SSA Headquarters, a Virginia SSA Field Office, a Virginia Disability Determination Service (DDS) office, and MedVirginia. Because the focus of the project was the transmission of data across the NHIN, it was important to understand the

perspectives of the other participants involved in this effort. To gain a broader perspective, interviews were also conducted with ONC officials, staff, and representatives who are responsible for the NHIN, and with FHA, which is responsible for bringing together Federal partners to deliver the open source CONNECT gateway. Interviews were also conducted with representatives from the organization responsible for the development and support of the CONNECT software. Additional interviews were conducted with key personnel from Bon Secours Health System, the participating MedVirginia provider, as well as a benefit qualification vendor under contract with Bon Secours.

A total of 43 people participated in the interviews (See Appendix A for an interview listing and Appendix B for interview questions). Informational documents were collected from SSA, MedVirginia, and Bon Secours. Targeted literature reviews were also conducted (See References). Analysis was then performed to understand the benefits and challenges of requesting and submitting health information across the NHIN as well as to gain insight into cross-cutting metrics of success and key issues across all domains.

The analysis involved three phases for categorizing the interview responses:

1. Organizing responses from the interviews into three domains: technical, organizational, and governance.
2. Organizing the responses by the dimensions within each domain, identifying challenges, successes, and considerations moving forward.
3. Identifying response patterns as a means of gaining insight into cross-cutting metrics of success across the domains.

Findings

The findings of this study are organized in sections across three domains: technical, organizational, and governance, and conclude with a section on cross-cutting metrics of success. Each section discusses challenges, successes, and considerations for moving forward specific to the authorized request and submission of health information across the NHIN. Collectively, the findings not only provide a retrospective account of this project, but also offer insight to SSA, MedVirginia, and other providers which may be expanding or undertaking similar endeavors.

Technical

This SSA-MedVirginia-NHIN project entailed a range of technical activities to achieve successful authorized request for, receipt, and transmission of patient health information. For SSA this meant transmitting an authorized request to MedVirginia (including the image of the signed Form 827), for MedVirginia it meant communicating with the NHIN to receive the authorized request and send the health information, and for the NHIN it meant providing a secure transmission mechanism.

The findings for the technical domain are summarized in Table 1.

Table 1. Technical Challenges, Successes, and Considerations Moving Forward

Challenges	Successes	Moving Forward
•MedVirginia gateway communication •Authorized request for information using standards	•Transmission of semantically interoperable live data •CCD creation	•Use of open source CONNECT gateway •Technical readiness

Challenges

The two main technical challenges identified are gateway connectivity and the authorized request for information. The transmission of data across the NHIN requires a gateway. This gateway connects the organization's systems with the NHIN and provides the conversion of communication protocols allowing authorized release of health information from the organization to move across the NHIN in a standard format. MedVirginia already had a gateway mechanism in place from the Trial Implementation, and for the limited production implementation with SSA, used their existing gateway. For the SSA implementation, it took a significant amount of effort to ensure communication from MedVirginia's clinical repository system to the gateway. While MedVirginia's original gateway provided proper interoperability, MedVirginia decided to change from their existing gateway to the FHA CONNECT gateway. Using FHA's CONNECT gateway allows for seamless revision updates resulting from maturing Health IT standards and also allows MedVirginia to be part of the CONNECT user community. It was noted by those at MedVirginia that internalizing operations aligns with their philosophy, and when CONNECT became available, the change seemed logical. Changing from the original gateway to the CONNECT gateway required MedVirginia to make significant modifications to their existing adaptors that join their clinical repository system to the gateway. This demonstrated that even though both gateways were built according to the same specifications, there can be variations, thus illustrating that gateways are not seamlessly interchangeable. However, those at MedVirginia expressed that the long term benefits and resource conservation outweighed the upfront efforts.

Provider response to SSA's request for authorized request for information requires a signed Form 827. In the NHIN environment, transmission of the signed Form 827 required using a technical standard that would be applicable to any provider. However, a specific and acceptable standard did not exist. As explained by a project team member, "This took 4 to 6 weeks, working with the various partners to identify existing HITSP standards consistent with authorization, security, and access permission. Then we found a place within two existing NHIN transaction standards, XACML[15] and SAML,[16] which did not prohibit the placement of the authorization, accommodated an image, and maintained compliance with both standards." The approach satisfied the standards requirements as well as MedVirginia's requirement to assure that the authorization was present while also granting access to the authorization in the event viewing was necessary before releasing the medical evidence. Once the approach was determined, MedVirginia put in place the capability to receive the

[15] XACML is an XML based standard used to represent and evaluate access control policies defining the mechanism for creating the rules and policy sets that enable meaningful authorization decisions [6].
[16] SAML is an XML based standard for exchanging authentication and authorization data between an identity provider and a service provider [7].

patient authorization in the "unsolicited notify" transaction which is defined in the Health Information Event Messaging (HIEM) specification.[17]

Successes

The overarching technical success was the transmission of semantically interoperable live health information via the NHIN. Accomplishing this data transmission required working through some of the NHIN specific complexities outlined in the Challenges section and through additional non-NHIN specific difficulties such as CCD[18] creation which was central to the ability to send useable information to SSA.

This first use of the NHIN for the authorized request for, transmission, and receipt of health information to support disability claims demonstrates the value of a nationwide health information exchange. SSA and MedVirginia have demonstrated the usability of the NHIN for expeditious request for and submission of medical evidence.

The successful electronic receipt of medical evidence furthers SSA's efforts to reduce the amount of time a claimant must wait for a disability determination. According to information provided by SSA, during the period of March 1, 2009 to September 4, 2009, the mean case processing time for the MEGAHIT (electronically transmitted) cases transmitted across the NHIN was 59 days. Compared to the Virginia DDS state average of approximately 84 days, this translates to an average case processing time savings of approximately 42%. While the number of electronic cases generated in this limited production effort is relatively few, these results illustrate the potential for reducing case processing time. More importantly, these results are consistent with the 41% time savings reported in the previous effort with BIDMC. As more providers participate in this electronic authorized request for and receipt of health information (and as fewer rely on the paper process), evidence suggests that the claimants, the providers, and SSA will all benefit from the increased efficiencies.

Considerations Moving Forward

Major considerations for moving forward center around advances that may be possible with using the CONNECT gateway to connect providers to the NHIN. Overall, there was shared optimism and enthusiasm about the technical feasibility of utilizing the NHIN to engage additional providers in electronic medical evidence submission. With interoperability standards and core technology packaged into an open source solution, the CONNECT gateway enables users to become part of a community of users for collaboration and collective feedback. This shared knowledge could help new participants save time, thus allowing for focus on implementation. In terms of implementation, technical readiness for health information sharing requires a specialized skill set and body of knowledge. As noted by an SSA representative, "Once you have seen one CCD, you have seen *one* CCD, they are all unique." Therefore, a CCD "validator" could discover, test, and resolve data ambiguities and may bridge this skill and knowledge gap. As providers migrate towards full implementation of electronic records challenges with multiple CCDs for each patient (i.e. one per visit) are foreseeable. Because MedVirginia has a centralized database model (all data for one patient resides in the same place), producing a consolidated CCD was feasible. However, future

[17] Unsolicited notify refers to an electronic notification that occurs to the recipient by the sender that a change has taken place. This notification is not dependent on the recipient "asking" the sender's server if the information has changed.

[18] The CCD is not meant to replace medical information, but merely to provide a core set of relevant health information [8]. The CCD produced by MedVirginia contains health information, which could support disability determination.

HIEs with distributed database models (patient data residing in different databases), may have to determine efficient CCD consolidation methods. In light of these and other issues, many of those interviewed cautioned against moving too quickly and bringing too many providers online concurrently and recommended staggering future implementations.

Organizational

Organizational factors also were instrumental to the success of the SSA-MedVirginia-NHIN project. A short project timeline increased the time-sensitive issues of completing the tasks within the accelerated timeframe. A project announcement in mid-December 2008 and a "go live" date of February 28, 2009 meant accomplishing this project in just over two months. This accelerated effort also impacted ONC as it was faced with transporting live data in limited production as opposed to test data in trial implementations.

The findings for the Organizational domain are summarized in Table 2.

Table 2. Organizational Challenges, Successes, and Considerations Moving Forward

Challenges	Successes	Moving Forward
•Stakeholder value proposition •Communication	•Leadership •Collaboration	•HIE value proposition •Data transparency

Challenges

There were two main challenges in this multiorganizational endeavor: perceived value proposition variances and communication. Even when public and private organizations have a common vision, there are frequently varying perceptions of value propositions. In this case, MedVirginia's motivations to use the NHIN as a secure transport mechanism were aligned with SSA's. Both MedVirginia and SSA were clearly interested in contributing to the improved efficiencies that Health IT can bring to the authorized request for and release of health information for disability determination.

While MedVirginia has a clear understanding of their value proposition, challenges existed for one of their providers (Bon Secours) with respect to perceived sustained value in subscribing to an HIE that was participating in the NHIN. Bon Secours noted some challenges with demonstrating near term return on investment (ROI) and incentive alignment, commenting, "We want to make sure that when we have someone who can qualify for benefits that we do so – this is of benefit to the patient, to us, and to our competition, but we have to recognize the potential misalignment of incentives with this model, and this can affect our short term recoverable dollars." In other words, from a provider's ROI perspective, the sooner the provider can recover costs, the stronger the perceived value proposition, even if the benefits secured translate into delayed compensation.

The SSA-MedVirginia-NHIN project required multiple levels of communication among the many parties involved, and maintaining a constant level of communication among the various stakeholders and their teams proved challenging. The total number of involved parties further complicated communication. For example, part of MedVirginia's development team was outsourced

to Dubai creating time zone difficulties for critical meetings involving technical issues. The project required frequent phone calls, sometimes 6-7 per day, each with many participants. While most noted this as a challenge, a few thought this level of communication fostered close collaboration and helped keep everyone focused and moving in the same direction throughout the project.

Successes

Organizational successes centered on leadership and collaboration. All parties spent considerable effort to ensure successful practices were followed and several cited the "visionary leadership to just move forward" as an important motivating factor. A general sentiment expressed throughout the interviews was that all organizations recognized that this was a cutting edge project with significant nationwide implications for secure and interoperable health information exchange. The idea of being the first example of utlizing the NHIN for live information exchanges inspired participants to execute the mechanics of this project within a very tight timeframe. From the outset, leadership support for extensive efforts to push the project forward included representation and participation in all appropriate Health IT committees and workgroups (including technical, policy, and standards). This involvement cultivated ownership and empowerment and created a high level of sustained motivation from all organizations. The mutual respect for the leadership within and between organizations was discussed by many. All parties realized that in order to accomplish the project goals, a high degree of interdependence was necessary and the leadership fostered effective team collaboration. One MedVirginia interviewee enthusiastically noted, "We all knew there would be a number of things that would need to be worked on and the fact that all sides have committed, no matter what, is a comment about the fortitude and will power of these organizations to stick to it until issues were resolved – that is a hallmark of success that everybody could be proud of!"

In terms of collaboration, project participants recognized the remarkable level of simultaneous effort within and between the organizations to accomplish information sharing across organizational boundaries. While interviewees attributed this perseverance to a variety of factors, all agree that organizational guidance and vision were critical. These aspects fostered the agility necessary to adapt to the many changes that arose during the short implementation time. For example, MedVirginia was not collecting emergency department (ED) notes in their repository and they were not including International Classification of Diseases (ICD-9) diagnosis and Current Procedural Terminology (CPT-4) procedure codes in the CCD. MedVirgina resolved these omissions, stating, "Once we realized that we should and could include this information, we pushed to get this improvement done."

Considerations Moving Forward

Considerations moving forward include understanding each stakeholder's perceived value propositions and incorporating a level of transparency that fosters communication and collaboration.

The sustainability of this effort is fundamentally predicated on all parties perceiving an enduring value for their participation. From the providers' perspective, the sooner claimants have disability benefits, the sooner they may be considered for receiving public health benefits (e.g. Medicare, Medicaid), if applicable, translating into uncompensated care cost recovery.[19] Uncompensated care cost recovery can be an element of the value proposition for providers. Those from MedVirginia discussed cost recovery for uncompensated care as a tangible and quantifiable key metric for

[19] Uncompensated care is defined as the cost of care not paid for out of pocket or by private or public insurance sources, including charity care. Uncompensated care excludes underpayment by Medicare and Medicaid [9].

sustainability and of value beyond this limited production effort (see the Cross-cutting Metrics of Success section).

In terms of transparency, interviewees discussed that it would have potentially saved time if the data elements needed and used by SSA and the data availability from MedVirginia had been better clarified in the beginning. For instance, even though SSA provided MedVirginia with a checklist of data elements, each organization spent valuable time attempting to understand and identify the data needed by SSA as compared to data held by MedVirginia. This process is further complicated by data ownership. For example, MedVirginia's EHR use of the tilde (~) differed with SSA's use of the tilde. This incompatibility caused data translation issues. This issue has yet to be resolved because MedVirginia cannot modify the data. While a workaround for this has been established, it is representative of the nuances facing future partners and SSA. Many discussed the need for standard procedures and best practices to achieve data transparency for efficient processes.

Governance

Intra- and inter-organizational authority (delegations of decision making power) and clear role definition have been shown to foster a more cooperative environment of information sharing and decrease intra- and inter-organizational issues [10]. Furthermore, the nature of the relationships between decision makers is important in navigating variable governance processes and structures [11, 12] and sharing decisions [13]. Governance is the establishment of oversight, standardized policies and procedures, and mechanisms to ensure operation of an organization.

Findings from the Governance domain are summarized in Table 3.

Table 3. Governance Challenges, Successes, and Considerations Moving Forward

Challenges	Successes	Moving Forward
•DURSA •Certificate Authority •Service Level Agreement •Privacy and security	•Ad-hoc governance structure	•Formal governance structure •Privacy and security

Challenges

The sustained transmission of patient data across the NHIN cannot occur without end-to-end governance structures in place. Two key governance challenges emerged in the SSA-MedVirginia-NHIN project: a formalized governance structure and privacy and security. Formalizing a governance structure includes a Data Use and Reciprocal Support Agreement (DURSA), Certificate Authority (CA), and Service Level Agreement (SLA).

Data sharing requires data use agreements between entities. This limited production effort brought to light the challenges in sustaining such a practice and the subsequent need for a DURSA in which a "trust" agreement sets forth a common set of rules and practices to support participants exchanging health information across the NHIN. Furthermore, the reciprocal nature of a DURSA underscores the value of such a mechanism in eliminating the need for arranging and managing multiple data use agreements.

In terms of a Certificate Authority, each new exchange or handshake requires a means for the entities to recognize one another. A Certificate Authority, which is the mechanism used to recognize and authorize an exchange, is a digital certificate issued by a trusted third party (e.g. Verisign is a commonly known Certificate Authority). Due to the lack of a Certificate Authority, the SSA-MedVirginia-NHIN project required multiple self-signed certificates (a certificate signed by its own creator). Signed certificates were needed for each environment (test, validation, production). Interviewees noted that the process used for this project is neither scalable nor sustainable. Consequently, the project validated the need for a single Certificate Authority process that would issue digital certificates and certify credentials for NHIN participation.

In terms of Service Level Agreements, no prior agreements existed for this project leading to misaligned expectations regarding serviceability, response times, and responsibility. In the absence of Service Level Agreements, close team collaboration facilitated the ability to work through any issues encountered. For example, when MedVirginia experienced occasional outages, the informally adopted procedure involved a phone call from SSA to MedVirginia. Investigation within MedVirginia had the system back on line as soon as possible, however many noted this is not sustainable or best practice.

Core privacy and security principles applying to the NHIN exist within the Health Insurance Portability and Accountability Act (HIPAA) and the Federal Information Security Management Act of 2002 (FISMA).[20] Even so, challenges were noted relative to:

- Limitations on information collection (how much information is collected and how it is used)
- Disclosure of information (what is in the record)
- Precautions against misuse of data (maintaining security precautions and tracking disclosure breaches)
- Audit trails (being able to see who viewed what and when)

Interviewees noted that as a Federal Agency, SSA is required to comply with FISMA but the providers receiving the request do not. However, because the SSA process includes a signed authorization from the claimant (Form 827), the information can be sent without having FISMA authentication from the provider. Additionally, MedVirginia has an "opt out" feature for sharing medical information in which patients can specify that they do not want their health information shared. Even though a Form 827 signed by the claimant gives SSA permission for the authorized release of information, challenges exist regarding alignment with other policies including HIPAA, local regulations, and local facility policies. As mentioned in the technical section, these challenges were addressed through the use of standards that allow for provider viewing of the From 827.

Successes

The innovative nature of this project tolerated an "ad-hoc" governance structure with shared interest by all parties. This structure facilitated accomplishment of tasks in a narrow time frame and accommodated some of the previously identified challenges. As noted by the NHIN Program

[20] FISMA is the Federal Information Security Management Act of 2002. It was passed as Title III of the E-Government Act (Public Law 107-347) in December 2002. FISMA requires each federal agency to develop, document, and implement an agency-wide program to provide information security for the information and information systems that support the operations and assets of the agency, including those provided or managed by another agency, contractor, or other source [14].

Director, "Communities of interest are a means by which to understand and fix issues and in these early stages of development is the way to get things done and should be continuously fostered."

Considerations Moving Forward

As ONC builds out the infrastructure to facilitate provider partnerships across the NHIN, a technical governance structure addressing identified challenges will help all parties have a shared understanding of expectations and procedures. Technical governance could provide oversight and standard processes, thus facilitating technical compatibility between all NHIN participants. This governance structure includes the need for a data use agreement, a Certificate Authority, and Service Level Agreements.

The need for development and implementation of a DURSA was deemed essential by participants, and ONC is currently in the process of creating a workable and sustainable data use agreement. The reciprocal nature of a DURSA eliminates the need for each organization to enact separate data use agreements with each other for standardized patient health information exchange rules and practices. The support for an ONC-chartered DURSA has been remarkable. An interviewee noted, "When you get 13-17 of the biggest players in healthcare to agree, somewhere someone is doing something right."

As mentioned in the challenges section of this domain, this project validated the need for a single issuing Certificate Authority for NHIN participants. Interviewees thought this could streamline mechanisms for participation. Additionally, it was thought that a single Certificate Authority could provide the means to create a Universal Description, Discovery, and Integration (UDDI) provider registry,[21] which in a broader sense, could subsequently serve to maintain information about each provider enabling future secure connections with other providers, thus fostering growth toward a larger and more scalable NHIN network.

Having Service Level Agreements in place is critical for moving forward, creating a shared understanding of performance expectations. Multiple providers and the potential for an exponential number of gateway end points require defined procedures for Service Level Agreements that would provide a clear and consistent understanding of the expectations and agreements for the level of service. One study participant expressed, "If someone is depending on a certain service, it is important to ensure that such a service is there for them."

Concerns surrounding privacy and security are inevitable, as health information data request and receipt increases between additional providers and SSA. One aspect of MedVirginia's solution to address these privacy concerns included the ability to view an electronic image of Form 827. As the NHIN scales up in use, the expectation is that there will be a subsequent series of privacy and security policies into which the Form 827 will be integrated. Each provider may have unique state or local policies governing limitations on disclosure of information influencing the extent to which certain information is shared (e.g. mental health or sensitive diagnosis information). Additionally, consumer preferences may play a role in limiting information collection by electronic means.

Cross-cutting Metrics of Success

This section outlines metrics of success across the three domains: technical, organizational, and governance. From a technical perspective, metrics of success are in terms of medical evidence

[21] A registry for organizations in which they can list their web services and find services of other organizations. This process uses a unique identifier that is linked to the organization (http://uddi.xml.org/).

receipt and mean case processing times (including preliminary analysis). Nearly all interviewed agreed that faster receipt of medical evidence coupled with the preliminary analysis afforded by MEGAHIT had a positive impact on mean case processing times. Moreover, this sequence could lead to more expeditious disability determinations, subsequently unlocking the potential for increased access to care (through the potential for Medicare or Medicaid). As reported earlier in this study, the receipt of medical evidence into the claimant's electronic folder was accomplished in approximately 2 minutes resulting in mean case processing time savings of 42% over the Virginia DDS state average. Anecdotal evidence suggests that some disability determination decisions may have been made faster with this electronic process. DDS examiners noted that having the medical evidence in a claimant's electronic folder when initially opened, together with guidance provided by MEGAHIT helps them to make a decision for an allowance much sooner than without those elements in place.[22] Additionally, examiners thought that the electronic medical evidence was more adequate (had enough of the right information) for disability determination as compared with the paper-based records. The value of this was summed up by a MedVirginia official, "To the extent that we are contributing to a better and faster decision and the people are going to get the benefits they are entitled to, this is a huge measure of success for us."

Many discussed the providers' and HIEs' perceived value propositions as central to organizational success in particular, and to the NHIN success in general. Interviewees from MedVirginia and Bon Secours described the authorized electronic release of health information across the NHIN as an incentive because of the potential for a faster disability determination that could lead to the potential recovery of uncompensated care. The practical side of uncompensated care cost recovery was described by an interviewee from MedVirginia as a patient who ordinarily would not have generated any revenue, but because benefit determination resulted in health benefits (Medicare or Medicaid), did generate revenue. Mechanisms such as the electronic release of health information that contribute to cost recovery can support the provider value proposition from many different aspects. Accounts Receivable (A/R) days are a metric that could be positively impacted by faster collection of medical evidence. Like many providers, Bon Secours uses an outside eligibility vendor to qualify patients for a variety of benefits, one of which is disability through SSA. Specific to disability benefits, the eligibility vendor reports an 86% conversion rate[23] with an average per patient cost burden of $600[24] and an estimated fiscal return averaging approximately 22% of gross hospital costs.[25] Vendor provided aggregate data (Medicare, Medicaid, Workers Compensation, etc.) are illustrative of the potential for cost recovery. Table 4 outlines aggregated and SSA specific fiscal recovery over a six-month period (August 2008-January 2009 [inclusive]) at 31% or $32m of 21,984 cases ($102.2m) of assumed uncompensated care cases. On an annualized basis, this 31% suggests a net dollar value of approximately $14m in actual recoverable provider revenue. Of this net dollar value, approximately 15% is SSA disability specific translating to approximately $2.1m. As mentioned, this is revenue that the facility would not necessarily collect otherwise. These data are suggestive of one area of potential provider value in using the NHIN for the exchange of medical information with SSA for disability determination. It is acknowledged that other potential value

[22] Denials require full medical evidence development to give every possible chance for coverage, whereas once the medical evidence supports an allowance, a favorable decision can be made.
[23] This is self-reported from the eligibility vendor. A conversion occurs when benefits are secured for a patient who otherwise would have been considered charity or uncompensated care.
[24] Cost burden is the per case cost of the eligibility vendor and varies greatly between eligibility vendors, some of which may be attorneys. The cost burden cited in this study does not include usual and customary costs (paid by the patient) on retroactive benefits.
[25] Gross hospital costs are the total dollar amount of non-discounted care (i.e. insurance or other "write-offs," etc.).

points, such as the time value of money, retroactive care cost recovery, repeat use of medical and community services, may exist that could factor into the ROI.

Table 4. Aggregate and SSA specific value of benefit determination for Bon Secours Richmond Health System*

	Aug 2008 – Jan 2009		Annualized	
	Cases	Value ($ millions)	Cases	Value ($ millions)
Referred	21,984	102.2	43,968	204.4
Converted (Gross $)	3,317	32.1	6,634	64.2
Success Rate	*15%*	*31%*	*15%*	*31%*
Net Recovered Costs		7.1		14.2
Success Rate		*22%*		*22%*
SSA Disability Specific				**2.1**

*Data are representative of the four acute care facilities within Bon Secours Richmond Health System only. Results may vary depending on demographics, locales, payer mix, etc. Data provided by Advanced Patient Advocacy.

Governance success might best be measured by the number of NHIN participants transmitting live health data to SSA. A formal governance structure and attention to privacy and security could help accommodate simultaneous transmission of health data across and increased use of the NHIN. Several interviewees noted that Health IT and the use of the NHIN have the potential to have an enormous impact on improving the overall disability determination process, especially the request and collection of medical evidence.

Conclusion and Directions

This nationally innovative effort has been successful in bringing to light the significance of and potential benefits for authorized electronic request and receipt of claimant health information across the NHIN for disability determination. As mentioned in SSA's Annual Performance Plan, "This initiative will revolutionize the way we process claims at all levels" [8 p. 23]. While it is too early and the numbers are too few to measure the true value of provider participation with SSA in the authorized request for and receipt of health information across the NHIN, the findings in this study are illustrative of the potential value for consumers, providers of healthcare, and Federal agencies such as SSA. As noted by an SSA official, "It's been extremely successful, it probably rates on a scale of 100 in the mid-90s – it's not perfect, and success does not mean perfection to us."

Recent developments with the American Recovery and Reinvestment Act of 2009 (ARRA) make it possible for SSA to accelerate efforts in using the NHIN for the authorized request and receipt of medical evidence. These accelerated efforts bring with them economies of scale for SSA to collect more medical evidence faster for more expeditious and consistent disability determinations, thus improving the speed and quality of the decisions and potentially reducing the backlog of disability determination cases. ARRA provisions to SSA are squarely aligned with SSA's strategic goal of eliminating the hearings backlog and preventing its recurrence and improving the speed and quality of the disability process [15]. SSA's use of Health IT is seen as an opportunity to help move

the nation forward in Health IT adoption and implementation at a time that may well be looked back on as a "tipping point in Health IT," as characterized by one interviewee.

In summary, much attention has been given to the proposition that Health IT can produce societal value relative to the investment. This SSA-MedVirginia-NHIN project is remarkable in that regard because it delivered on this proposition of successful authorized request and receipt of electronic health information across a secure and interoperable transport mechanism. Using medical evidence for disability determinations to illustrate broad national Health IT and NHIN usage, this project delivered value to multiple stakeholders, including the claimant. At the same time, this experience has illustrated the range of technical, organizational, and governance elements for consideration to ensure long term success and sustainability of such Health IT initiatives.

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Appendix A: Case Study Interview List

Organization	Person	Role
MedVirginia/ Bon Secours	Michael Matthews	CEO – MedVirginia
	Jean McGraw	COO – MedVirginia
	Joelle Buckner	CIO – MedVirginia
	Sandy McCleaf	NHIN Program Director – MedVirginia
	Nick Dawson	Director of Revenue – Bon Secours
	Jeff Burke	CIO – Bon Secours
	Joe Ingold	Vice President Integration – Bon Secours
SSA	Jim Borland	Office of the Commissioner
	Laura Train	Office of the Commissioner
	Bill Gray	Deputy Commissioner for Systems
	Justine Piereman	Office of the Deputy Commissioner for Systems
	Marty Prahl	Office of the Deputy Commissioner for Systems
	Shanks Kande	Office of the Deputy Commissioner for Systems
	Addy Naik	Office of the Deputy Commissioner for Systems
	Kay Welch	Office of Quality Performance
	Melissa Spencer	Office of Quality Performance
	Tom Ford	Office of Automation Support
	Robert Hastings	Office of Disability Programs
	Dorothy Hull	Office of Disability Programs
	Tony Notaro	Office of Disability Programs
	Jennifer Sherman	Office of Disability Programs
	Mike Zephir	Office of Disability Programs
	Ruth Lacey	Office of Disability Determination
	Brian Courtney	Office of Disability Determination
	Deborah Lynn	Office of Disability Determination
	Reggie Ewing	Office of Disability Determination
	Suzanne Payne	Office of Legislative and Regulatory Affairs
	Tom Davidson	Office of Disability Systems
	Rich Terzigni	Office of Telecommunication and Systems Operations Architecture
	Pam Waters	Office of Systems and Electronic Services
	Mike Levy	Office of Systems and Electronic Services
	Robbie Watts	Office of Disability, Appeals, and Review
VA DDS	Margie Dexter	Acting Director
	Gloria Ford	Professional Relations Coordinator – MEGAHIT Team Leader
	Others from DDS	4 Examiners, 2 IT Analysts
Harris	Bart Harmon	NHIN Developer and Support Supplier
HHS – FHA	Vish Sankaran	FHA Program Director
	Dave Riley	CONNECT Lead
	Craig Miller	CONNECT Chief Architect
	Vanessa Manchester	CONNECT Program Manager
HHS – ONC	Ginger Price	NHIN Program Director
	Mariann Yeager	NHIN Policy and Governance Lead
	Buff Colchagoff	NHIN Technical

Appendix B: Case Study Interview Questions

Technical

1. Please describe the technical processes involved in making this data sharing process successful.
2. Please describe technical barriers/advantages that contributed to the timeliness of this project.
3. Please describe the role that standards (or lack thereof) played in achieving technical functionality.
4. What do you see as the perceived value of providing medical evidence in this manner?
5. Please describe technical challenges for sustainability or growth.

Organizational

1. Please describe any changes to your organization's work process in terms of preparing, transmitting, and/or receiving electronic information using this process.
2. Please describe the challenges within your organization that emerged during this project, including challenges relating to sharing information with a collaborating organization.
3. What was the perceived value of this process to your organization's mission?
4. Please describe organizational challenges for sustainability or growth, both for your organization and in collaborating with another organization.
5. What initiatives are *currently* supported by your organization that may impact the content and/or approach to the development of the Preparedness Guide? What initiatives were *previously* completed or attempted?

Governance

1. Please describe any of your company/agency approvals that where necessary to make data sharing possible.
2. In relation to governance issues, what are the challenges faced by your organization in sharing data with another agency?
3. Please describe any legal considerations that emerged prior to or during the pilot.
4. What governance structures do you see as vital for sustainability or growth of this system?

Cross-cutting/Evaluation

1. Please discuss the extent to which various stakeholders, including consumers, (or claimants as was the case in the SSA-MedVirginia project), providers, and payer organizations stand to benefit from this system.
2. What metrics should be used to evaluate the success of this system and to what extent is that information being gathered?
3. How important are overall economic (cost-savings) and social benefit considerations in the success and support for such a process?
4. What do you see as some of the critical success/challenges factors of the pilot?
5. What do you think are the key ingredients to having a successful medical information exchange collaboration between public and private entities?
6. Have the various outreach efforts been successful? Why? Why Not? How would you define success of a SSA/NHIN campaign strategy?

Appendix C: Acronym List

A/R	Accounts Receivable
ARRA	American Recovery and Reinvestment Act
BIDMC	Beth Israel Deaconess Medical Center
CCD	Continuity of Care Document
CA	Certificate Authority
CPT-4	Current Procedural Terminology
DDS	Disability Determination Services
DURSA	Data Use and Reciprocal Support Agreement
ED	Emergency Department
EHR	Electronic Health Record
FHA	Federal Health Architecture
FISMA	Federal Information Security Management Act
Form 827	SSA Authorization to Disclose Information
Health IT	Health Information Technology
HHS	US Department of Health and Human Services
HIE	Health Information Exchange
HIEM	Health Information Event Messaging
HIPAA	Health Insurance Portability and Accountability Act
ICD-9	International Classification of Diseases
MEGAHIT	Medical Evidence Gathering and Analysis Through Health IT
NHIN	Nationwide Health Information Network
ONC	Office of the National Coordinator for Health IT
RHIO	Regional Health Information Organization
ROI	Return on Investment
SLA	Service Level Agreement
SSA	Social Security Administration