Final report for the National Multi Protocol Ensemble for Self -Scaling Systems for Health (NMESH)

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In this report we describe the original NMESH proposal, its motivation and component parts. We then go on to describe the multiple sub-projects that were undertaken to meet the goals of the NMESH proposal and then describe the surprising variety and scope of the successful spin-offs of the NMESH project. Figure 1 is a high-level architectural diagram of the NMESH proposal. It notably involves several component parts which we will describe shortly but it is it was clear from the outset that the overall goal was to use all available sources of current and emerging health care data to manage care effectively in peacetime and in disaster. The most conventional component of the NMESH proposal was electronic medical records systems (EMRS) based in their home institutions. Even then we foreshadowed what would eventually be called the regional health information organization (RHIO) movement by showing how these conventional EMRS's could be linked through a set of master patient indices that would allow a regional look up function; all secured and authenticated with an NMESH certificate of authority. However the proposal went considerably beyond traditional electronic medical records to encompass personally controlled electronic medical records, namely "virtual data sponges" that would accrete the life-long records of patients as they would travel from one health care system to another or as their health insurance or employment changed. This latter component was based on long-standing project with funding prior to the NMESH proposal by the National Library of Medicine in the Personally Internetworked Notary and Guardian, the PING [1] project, now known as the Indivo project [2-4]

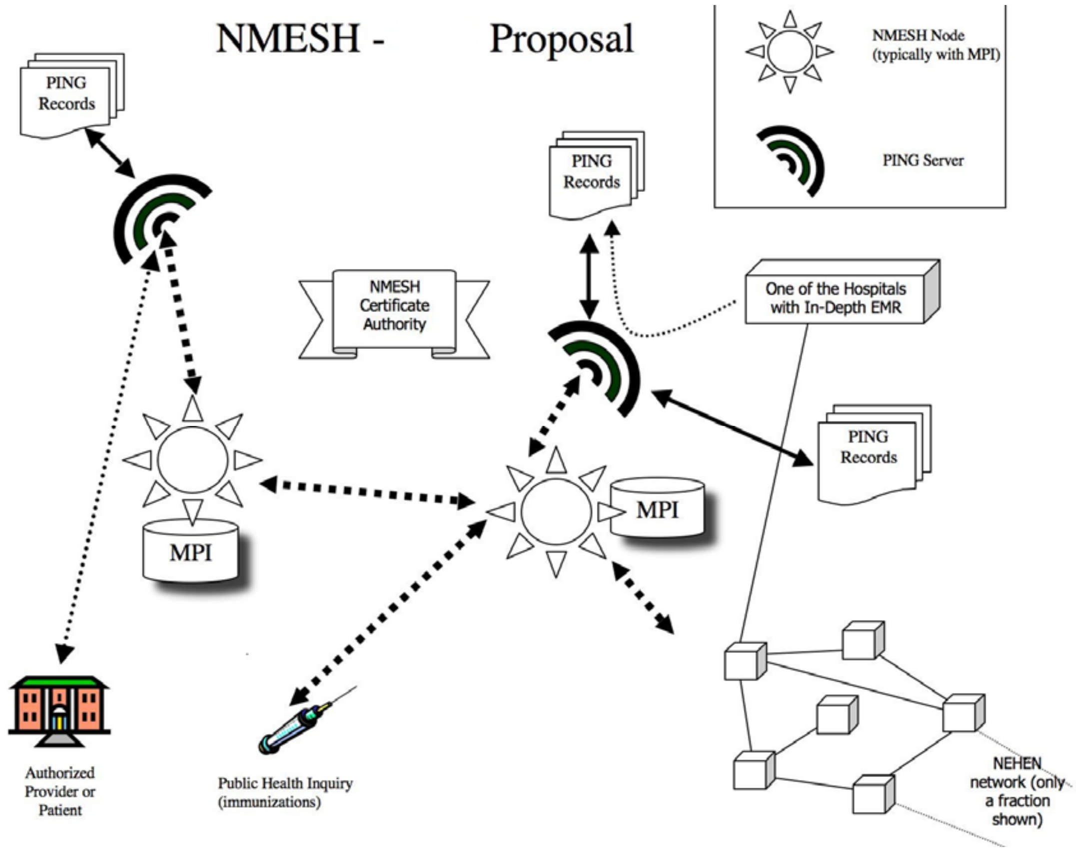

Figure 1: The Original NMESH Proposal to the NLM

The notion that a personally controlled health record could become an important part of a population-wide infrastructure was quite innovative at the time of the initial proposal and in no small part due to these activities it has now become an almost conventionally accepted component of population health care IT proposals in 2007, both by large commercial organizations and by large academic health centers [5]

Included in the initial proposal was extreme redundancy both along the lines of the redundancy first implemented in the Internet and using essentially the same decentralized structures. Again, as shown in Figure 1, we envisioned the application areas of NMESH to be both public health and clinical care applications. In doing so we had several process goals by which we would measure are own success. These included coming up with an architecture that was both feasible technically and sociological. We were all too aware based on several experiments in inter-institution data sharing that the sociological obstacles often exceeded the technical ones. We also wanted to ensure that the proposal would in fact scale to the national level and indeed be robust and useful in the case of disaster whether natural or man made. In addition to the NLM funded PING system, now known as the Indivo personally controlled health record, we were also leveraging a significant investment by the National Cancer Institute for the Shared Pathology Network for which Isaac Kohane was the Principal Investigator [6-10]. This system, designed to allow integrating searching for pathology samples across multiple, geographically dispersed and/or competing institutions, was successfully implemented at several national sites as a prototype including the Regenstrief Institute at Indiana, several Boston hospitals, Pittsburgh Medical Center and two UCLA hospitals. It was also implemented at the Dana Farber Harvard Cancer Center (DFHCC) where it functions as the Virtual Specimen Locator across 7 paraffin archives and tissue repositories and continues to grow, encompassing millions of patient specimens.

The AEGIS system provided both an the analytic back end for large population monitoring for NMESH as well as the user interface to provide at-a-glance understanding of temporal and special distributions of various disease burdens at the monitored areas [11-16]

All three components, Indivo, SPIN, AEGIS have all been released with open source licenses and they each have very active and independent user/developer communities.

The NMESH process was characterized first and foremost by the emphasis on technical and sociological adaptability. This was imperative because the architectural requirements had to change with the development of new standards, technologies, and eventually, the broader acceptance of the goals articulated in the NMESH proposal. To this point it was strategically useful that, from the outset, NMESH included leaders in setting national data interchange standards such as Dr. John Halamka of Harvard Medical School who chairs the national HITSP standard setting effort. The second important aspect of the NMESH process was making use of multiple available test beds to obtain a more robust understanding of the implementation challenges and implacability of the NMESH system. To this point we ensured that NMESH was included in the office of the National Coordination (ONC) demonstration projects as well as in several RHIO demonstration systems.

The third and essential process, as mandated by the original Broad Area Announcement by the National Library of Medicine was the establishment of an independent evaluation team, in this instance led by Professor Patti Brennan from the University of Wisconsin. This evaluation is appended at the end of this report. Notwithstanding, the foci and conclusions of the evaluation team included the following: First, with regard to the biomedical and social value of the proposed application, the Wisconsin team noted that the architectural and policy commitment to the serving the individual patient had to be explicit. To this end, the fact the observation that we provided commercial grade open source records integration that permitted individual control over access was seen in the report as a strongly positive feature of our project. Furthermore the observation that the NMESH project crossed state records was also deemed essential. The second important focus of the evaluation team was that NMESH provided significantly more insights into the potential value of the application to public health and that the combination of the AEGIS system with the multiple databases available through NMESH provided novel and useful additional functionality. The third element of the evaluation was with regard to the actual architecture elements and advanced network capabilities. In their evaluation the Wisconsin team noted that the peer-to-peer functionality provided by the Shared Pathology Informatics Network provided the capacity to retrieve every instance of a given query from each queried entity with high precision and high recall. They also correctly noted that the NMESH high performance testbed that implemented distributed file systems to promote improved performance was demonstrated but not the functionality to demonstrate failure recovery.

The flexibility in the nmesh process was indeed put to the test by the fairly significant changes that occurred in the national health care system and in health care information technology in the four years of the funded project. Among these was the establishment of the Office of National Coordinator, and within that office, the focus on personally controlled health records, biosurveillance and national health infrastructure. These obviously played to the strengths to the original nmesh proposal. Similarly the agendas put forth by the American Health Information Community (AHIC) group and the standards set by the Health Information Technology and Standards Panel (HITSP) process required a nimble and actively managed adaptation of nmesh implementations and architectures. NMESH was prominently featured at the HHS 3rd National Health Information Network forum. This was written up in JAMIA [17] and an accompanying editorial states, “This work moves informatics a critical step forward in providing an open architecture that can support translational research and interface with appropriate depth to systems for public heath and clinical care.” [18]

Finally at the national level the information flows, or lack of them, in the health care system around the Katrina hurricane disaster provided added impetus and motivation for the NMESH system. On the local level, in the Boston area, several developments allowed increased leverage in the demonstrations and applications of the NMESH technologies. This included the National Center for Biomedical Computing entitled “Informatics for Integrating Biology to the Bedside”(i2b2, see http://www.i2b2.org) whose PI is Isaac Kohane, the CDC Center for Excellence in Public Health Informatics for which Dr. Mandl is the co-PI and the Harvard Medical School Center for Biomedical Informatics for which Isaac Kohane is the co-Director.

Current Impacts

The 2007 ONC NHIN demonstrations and AHIC testimony both featured networked personally controlled health care record systems as well as point-to-point surveillance systems using NMESH components. The Indivo system that was the personal record component of NMESH was rolled out at Children’s Hospital Boston and at MIT Medical Services and the Massachusetts Share cooperative. It was also deployed with Hewlett Packard occupational health pilot. Most recently, it was announced [19]as one of the core platforms of the dossia [20] effort by which employers from many large companies would use Indivo as a basis of their employee’s independent and personally controlled health record systems. These companies, which include Intel, Wal-Mart, AT&T, Sanofi-Aventis, Pitney-Bowes, and British Petroleum in aggregate have well over 5 million employees which will serve as a very significant population test bed of the Indivo system and a potential future testbed for other NMESH components.

The Connecting for Health/Markle Foundation framework references NMESH technologies specifically, for example citing that "the SPIN network offered a way to build a network with a limited number of interfaces but could use those interfaces in different ways for different kinds of reporting. As a result we have been able to optimize our clinical reporting framework for that one purpose while using SPIN to provide public health reporting among the same entities." [21]. Other major SPIN implementations have included the National Cancer Institutes recent tissue sharing efforts among large HMO's, the caTIES Program (one of the more successful components of the caBIG Program). Furthermore several of NMESH technologies, both the population viewers as well as the peer-to-peer networking have been implemented by several CTSA awardees and applicants. Not least of the latter category is the Harvard medical School system which has over four major, independent hospital systems now in the process of being linked with these technologies.

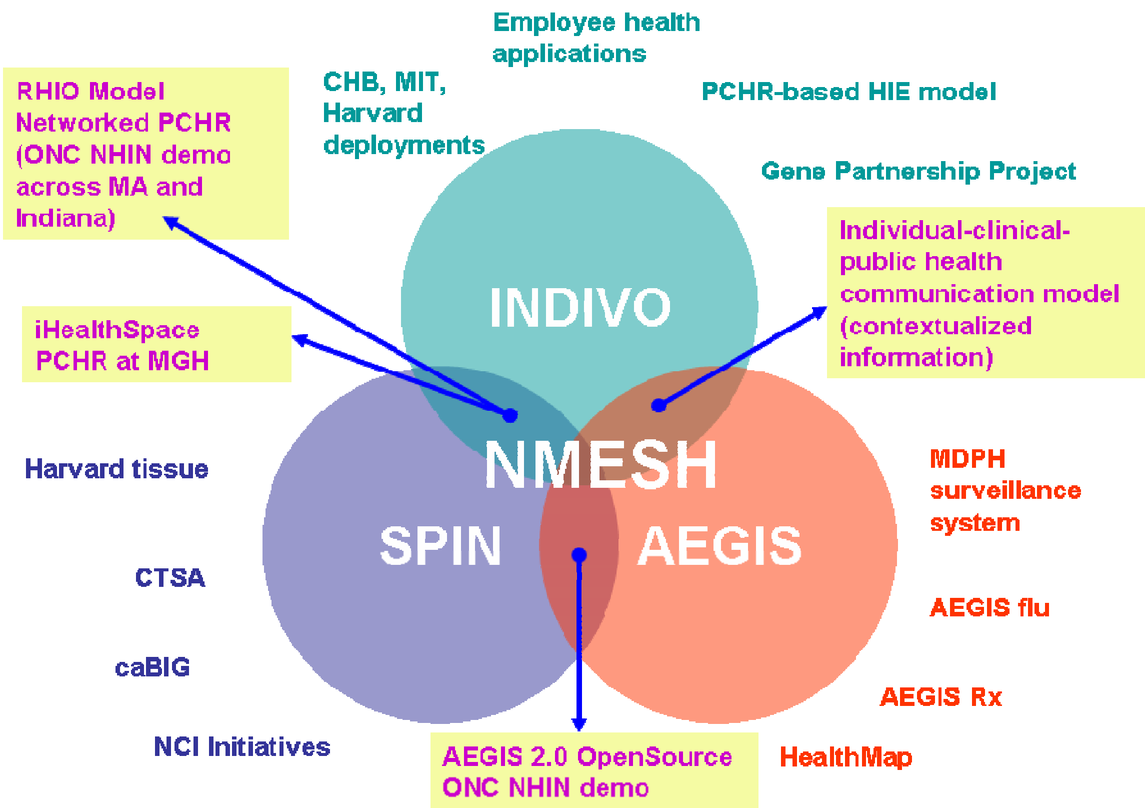

Figure 2: Confluence and spin-offs of the NMESH project

The Health Map project rose from the geographic information systems focus within nmesh and has resulted in several high profile applications in understanding the distribution of diseases of various stripes across the globe.[22] Finally the Informed Cohort [23] project exemplifies how state-of-the art genome wide measurements on the individual can be used today in concert with both institutional health care systems and personally controlled health records to provide population wide research cohorts while preserving individual autonomy and privacy in the process. In so doing, multiple nmesh components have been employed.

The confluence of all the projects directly derived from and driven by the NMESH project are diagrammed in Figure 2. Seen here are the three core components of NMESH: Indivo the personally controlled health record, Aegis the monitoring and analytic system, and SPIN the peer to peer query system. The nexus of high-visibility, high-impact activity that was germinated over a brief 4 year period by the original proposal with generous funding by the National Library of Medicine appears quite substantial in retrospect.

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Executive Summary
NMESH Independent Evaluation Subcontract
Brennan Health Systems Lab
October 1, 2007

Introduction

October 2007 marks the end of Year 4 of the NMESH project. This report summarizes the activities and accomplishments during the past four years of the project and evaluation team, and project status in relation to the previously-agreed upon project timetable (Appendix A). Each numbered paragraph is keyed to the corresponding numbered element of the timetable, with current status noted.

1. Project management oversight. Evaluation status: Completed

Project management oversight of NMESH was challenging for several reasons. First, NMESH evolved substantially over the project's four-year span because of emerging needs and opportunities not evident at the onset of the project, as well as unexpected constraints that unfolded as the project developed. The original evaluation framework was not sufficient to track these evolving changes, as outlined in Year 4 in the table below.

The NMESH project included stakeholders from a variety of organizations, and tracking the interplay between individuals in these organizations was challenging. Because the evaluation team was geographically distant from the project team, status updates were gleaned periodically from all project team members and more often from the project PIs and technical developer. It is unclear whether having an evaluator who was geographically close to the project team would have aided in understanding and mediating these interactions.

2. Baseline description. Evaluation status: Completed

The goal of NMESH involved pulling together people and existing technical components in a novel way. The original evaluation plan included describing three versions of NMESH: a cobbled-together version, a test bed version and a production version. The way these components were pulled together changed over time, however, so there were never any clear 'versions' of NMESH. The evaluation therefore describes the major underlying components of NMESH (PING, SPIN and AEGIS), and descriptions of how these components have been used in various instantiations. Year 4 was also aimed at understanding the non-technical, intellectual contributions of NMESH.

3. Performance testing. Evaluation status: Not completed

Performance testing was likely the most challenging piece of NMESH. This task was originally under the authority of MIT and was dealt with mainly by two graduate students. The first student attempted to use a tool called OceanStore as the basis to create an NMESH testing environment, but could not successfully get this tool to fulfill the needs of NMESH performance testing. A second student took over this portion of the project and switched focus to comparing the Chord and Master-slave approaches of distributed data storage. The student worked with the Chord developers at MIT to complete that portion of the study, but could not complete the Master-slave comparison because Indivo nodes could not handle transmitting large file sizes. The Indivo developers had other commitments and adding this capability for performance testing was not a priority. The student then changed focus to generating a policy analysis comparing various RHIO architectures.

4. Monitoring and documenting security. Evaluation status: Not completed

While there were some security statements and protocols generated as a part of NMESH, the lack of a testbed environment did not allow the project team to test the effects of various security strategies on the system in a simulated environment.

5. Assessing integrity of 100-user feasibility and impact experiment. Evaluation status: Completed

The user testing generated by the NMESH team did not take an experimental form. Instead, the NMESH team used live instantiations of their projects to understand user experiences with the projects. The projects included the influenza surveys at HP and extension to MIT. The evaluation team added two activities in year 4 aimed at understand how lay people view systems such as NMESH and what choices they would make to share their information through a system such as Indivo, within NMESH.

6. Human factors / usability study of mobile phone interface. Evaluation status: Completed

The usability study of the mobile phone interface was not a major component of NMESH and was largely eliminated. Instead, the project team examined the feasibility of using cell phone for authentication.

7. Experimental, general public and professional user profiles. Evaluation status: Completed

This task was completed in year 3 through a project done by one of the evaluation team members. The team member drafted use cases and interviewed patients to gauge their understanding of NMESH and these drafted use cases.

8. Economic analysis. Evaluation status: Completed

Directed by Dr. Mary Ellen Murray we developed a preliminary model for assessing economic considerations impacting health information network formation and participation. These considerations included the applications and limitations of normal market concepts such as supply, demand, pricing of goods, and production process modeling; the importance to institutions of both financial and non-financial decision-making; and the distinctions among 3 classes of institutional network decisions: creating, participating in, and maintaining a health information network.

We developed an economic model of NMESH as a multi-component, leveraged and forked-development project (where pre-existing architecture and development may be adapted for use in NMESH, but may continue to be developed and used for other purposes outside of NMESH). In lieu of traditional economic analyses, the project team has used its knowledge gained through the NMESH project to develop a funded NIH proposal. This new proposal, *Modeling participation in the NHII*, will use operations research modeling approaches to develop tools that health information exchange operations such as NMESH can use in their business decision making (Appendix P). These tools are likely more appropriate for this domain than traditional economic analysis because of the significant uncertainty embedded in the decisions made by operations such as NMESH.

A summary work plan follows this Executive Summary.

Calendar Year:	2003		2004				2005				2006			
		Project Year 1				*Project Year 2*				*Project Year 3*				
Quarter:		1	2	3	4	1	2	3	4	1	2	3	4	
Boston Team NMESH Project Element:														
Demonstration “Cobbled” Version			Cobbled											
Test Bed						Test Bed								
Production									Production					
Wisconsin Team Evaluation Task:														
1. *Project Management Oversight*														
Meet with NMESH team in Boston			X											
Establish Work Plan		X	X											
Monitor and Document System Implementation in Quarterly, Annual, Final Reports		X	X	X	X	X	X	X	X	X	X	X	X	
2. *Create baseline description of 3 implementations of NMESH and components*			X	X		X			X					
3. *Performance Testing*														
Describe Boston team performance testing				X			X		X					
Establish, oversee and assess time-and-transport study						X	X	X	X					
Establish, oversee and assess biohazard and network failure scenarios						X	X			X	X			
4. *Monitoring and documenting security of NMESH*				X	X			X	X			X	X	
5. *Assess Integrity of 100-User Feasibility and Impact Experiment*									X	X	X			
6. *Human Factors/Usability Study of Mobile Phone Interface*						X	X	X	X	X				
7. *Experimental, general public and professional user profiles*					X				X	X	X			
8. *Economic Analysis*														
Data Collection and Cost Estimation			X	X	X	X	X	X	X	X				
Resource Cost Analysis						X	X	X	X	X	X	X	X	
Production Process Modeling										X	X	X	X	