
Creating a Health Care Virtual Community: Northern New York Health Information System (NNYHIS)

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ABSTRACT

One of the potentially most significant emerging trends in telecommunications for the 1990's is the rapid growth and acceptance of low-cost, easy to use, wide area communication networks. The best example of this trend is the phenomenal growth of the global network: the Internet. This paper presents a prototype of a Internet-based, knowledge-sharing system that demonstrates the feasibility of utilizing low cost, available technologies to create an electronic gathering place in which county health representatives, healthcare providers and other interested parties can "meet" and share information.

INTRODUCTION

Perhaps one of the most exciting emerging trends in telecommunications for the 1990's is the phenomenal growth in wide-area, even global communication networks that can be relatively easily accessed by computer users. The metaphor used most often to describe this phenomena is the *information highway*, which can be viewed as an initial understanding of what is possible with the widespread growth of communication networks. Once this technological infrastructure is in place, then a new metaphor is possible as people interact and develop relationships via this new communication media: the network as an electronic gathering place.

In looking at the experience of one organization with their organizational electronic conferencing system, Zuboff [42] talked about *technology as place* due to its ability to provide new ways for individuals to "meet" and interact with each other without physically being in the same location. Rheingold's "The Virtual Community" [34] explored computer-mediated social groups that evolve over time as technology enables a very new way for people to "gather" together. In describing a virtual community based on a system called the *WELL*, Rheingold says "I watched the community's social contracts stretch and change as the people who discovered and started building the *WELL* in its first year or two were joined by so many others. Norms were established, challenged, changed, reestablished, rechallenged, in a kind of speeded-up social evolution" [34, p. 2].

One very successful approach using the metaphor of

creating an electronic gathering place is the *Freenet*, originally developed in Cleveland and hosted at Case Western Reserve. Freenets are grassroots systems designed to allow easy access to electronic services to a community [22]. When users log on to a Freenet system they are presented with a menu based on a town that the users can "walk" through and visit various "buildings" to access the services within. This provides a very intuitive, non-threatening interface for new users.

The ability to provide a relatively inexpensive, easy to use, electronic "place" in which users can share information has a great deal of relevance for the problems associated with rural healthcare. The use of telecommunications technologies to help deliver health-related services has increased over the past few decades [16]. Telecommunications facilitates health-care delivery over large distances — assisting with problems of geographic maldistribution of medical facilities, services, and personnel [16] [2]. Services provided can include diagnostic medicine, communication between doctors for consultation, and communication between groups and individual health practitioners and other professionals for education and training.

Surmounting the problems associated with geographical barriers is particularly crucial for health-care organizations in sparsely populated rural settings. Health-care has been identified as a critical area essential for the development of viable rural life and one in which telecommunications can play a significant role [12]. However, many rural areas experience higher unemployment and poverty rates than urban

areas. Reductions in Federal and State assistance necessitate that any consideration of information technologies must be low-cost for both public and private organizations. As Emery [8] explains: "If information age technologies diffuse only where business demand can justify the expense, most rural citizens will not enjoy the many benefits that information technologies can provide". A "healthy" telecommunications system, aside from being easy to use, must be cost effective, flexible, sensibly integrated and secure. Additionally, it should be easily monitored, and provide clients with services that are most essential [41].

Several rural applications have been undertaken in recent years, in the United States and elsewhere. PHOCUS (Primary Health Orientated Computer Users' System) links primary health care practitioners throughout isolated rural and outback areas of Australia [40]. Researchers in Canada are attempting to use available technologies to address the problems of distance in rural Saskatchewan [21]. The technologies include SmartCards (for province-wide access to patient records), satellite and fiber-optic links for distance education, and teleradiology for distance diagnostics. In Quebec, the TELEHEALTH system provides video and audio health information through telecommunications [35]. HealthNET, produced by Boston University, has provided remote neighborhood health centers and community hospitals the opportunity to participate in bi-weekly teleconferences on up-to-minute medical issues. Continuing education courses have been offered to physicians, nurses, pharmacists, social workers, nutritionists, and others [7]. The Telecommunications Information Network provides an information link between the University of Cincinnati Medical Center and health-care providers at rural and semi-rural hospitals in southwest Ohio [23]. Telemedicine has been applied to improve health conditions of Native Americans in southern Arizona [15]. Efforts are underway in Indiana to develop an Integrated Medical System (IMS), a statewide community network, to provide a link between hospital and physicians for clinical information [31].

All of the efforts we cite are most useful for specific functions or individuals. The high cost technology employed and the privilege of use are not widely distributed. Alternatively, the low cost and widely employed capabilities of Internet are seldom exploited within the health care community.

While the health care industry is one of the most prominent fields in which to apply advanced computer technology, public health departments and health education institutions have made little use of low-cost community computing technology. This paper will describe an effort that is underway, in conjunction with the St. Lawrence County Department of Public Health, to build a health care network in Northern New York State. The feasibility of a high utility,

low-cost knowledge sharing system will be demonstrated through a discussion of the *NNYHIS* (Northern New York Health Information System). *NNYHIS* is a prototype designed for low-cost, easy access to health care information and services. In the spirit of the Freenets, *NNYHIS* is designed to provide an electronic gathering place for healthcare providers, professionals and the general population. Like the Freenets our system provides a range of computing services and information access for a diverse client base. However, our project differs from the Freenet concept, in that, for reasons of security, users must be allocated varying privileges to access information and services based on their role in the health care community.

THE INTERNET

Although there are currently a number of wide-area communications networks in existence [33] [10] [26], and a new one — the National Research and Education Network (NREN) — is currently being considered by the US government [18] [30], at this point the fastest growing global network is the *Internet*. With its roots in a Department of Defense funded project in the late 1960's, the Internet only had an estimated 80,000 computers as recently as 1990. Currently it is growing at a rate of approximately 1,000 computers daily, and is expected to have close to 1,000,000 computers by 1995 [11].

Until recently the Internet was populated primarily by Department of Defense and other university researchers. This is no longer the case. The growth statistics of the Internet indicate the increasingly broad-base of new users. While university faculty and students provide a significant percentage of Internet users, the demand for access to the network outside of universities has generated a new type of company whose sole purpose is to provide access to the Internet for corporations as well as individuals [29] [17] [28].

The rapidly increasing visibility and accessibility of the Internet is also reflected in the number of recent how-to books describing how to use the Internet [6] [11] [20] [24] [25]. And increasingly the popular press — both periodicals and newspapers — are becoming aware of this phenomena [19] [4] [36] [39] [5] [37].

The combination of increasing awareness of the Internet by potential users with decreasing barriers to accessing the network provides an ideal technological basis for building an electronic gathering place in which information can be shared between the health department, regional healthcare providers and interested members of the public. The Internet provides tools for remotely logging on to other computer systems, retrieving files from other computer sites as well as making them available on your system to outside users, electronic

mail, discussion groups and access to the myriad of resources that are increasingly available via the network [22].

The unregulated, informal "atmosphere" of the Internet is also very conducive to the development of a grass-roots, community based network of users interested in receiving and sharing timely information about health care, education, technology, government, and recreation. A multi-user server computer can be established at a central location, and anyone with access to the Internet, or who has a personal computer (PC) and a modem, can access the server and get the services. Development of such community based computer networks represent a largely untapped potential for the dissemination, sharing and discussing of crucial health care information. *NNYHIS* was designed to demonstrate the possibilities which this type of technology has in creating a new medium of communication among healthcare organizations and individuals.

BACKGROUND OF THE PROBLEM

St. Lawrence County in Northern New York is the largest county, in terms of geographic size, in New York State. However, it is also one of the most rural, where the opportunities for sharing information and expertise are significantly diminished by distance. The County Department of Public Health has expressed a need for a system to provide an efficient and reliable way to receive and convey important information — including urgent notices and services — to the public, as well as to health care providers. The Department of Public Health recognizes that such a system would not only provide direct benefits for them, but also would provide a means for health care providers (e.g. doctors, hospitals, nursing homes etc.) to communicate and collaborate amongst themselves. Additionally, the general public would have access to relevant information either directly or through health care providers.

In the health care environment, effective, time-displaced communication is essential. While e-mail, voice mail, bulletin board systems, and facsimile (FAX) exist for communication, only FAX is extensively used. There exists limited exploitation of these other tools by end-users outside of large organizations. The Director of Public Health has expressed dismay over the slowness of FAX, especially when attempting to broadcast to a mailing list.

In addition to education, many public health activities involve collecting data from a wide variety of sources; consolidating, analyzing, developing graphical representations, and conducting statistical analysis. Some data are maintained solely for County planning purposes, while other information is provided to the New York State Department of Public Health for analysis and planning. A problem facing the County Public Health Department is the massive amount of data coming from different sources, at several

different times, via different communication media, during the course of the planning year. Often these data are years out of date. Public health officials want to short-cut the loop of data gathering and dissemination of those data needed for current decisions.

Requirements and Constraints

The Public Health Department identified a list of services that would address their most immediate needs. These were:

1. A means to gather and disseminate information of interest from and to the general public, law enforcement agencies, schools, news offices (television, radio, and print media), and health care providers (hospitals, private physicians, pharmacies, nursing homes, etc.).
2. The ability to upload and download files between the Department and health care providers.
3. The ability to send private messages to individuals as well as broadcast to specific groups of individuals.

Four broad system requirements were also identified through discussions with Public Health officials. Any system to be developed had to have the following attributes:

(1) **Low-cost implementation.** This necessitated use of low-cost, widely available technology for development in order to reduce economic barriers to participation. Any user, with a minimum of a 286 PC and a client modem and communication software (purchased for less than \$100), should have access to the services provided by *NNYHIS*. Given that most health care providers, law enforcement agencies, news services, and schools have computers in their facilities, the cost would be negligible. Additionally, computers are accessible to the general public at home and through libraries and continuing education programs.

(2) **Ease of use.** Widespread participation by decentralized end-users is often hampered by the complexity of emergent technology. The client base, in this project, is diverse in terms of technical expertise — from the novice computer user to an experienced information technician. Building a strong user base is dependent on clear explanations of the technical issues necessary to understand and effectively use *NNYHIS*. As such, a friendly server interface that facilitates all clients to explore available services was desired. Ease of use, in conjunction with the requirement that the system would be accessible via a modem from a 286 PC, necessitated the construction of an explicit text-based menu driven system to guide both experienced and entry-level computer users.

(3) **Security.** While the health network is designed to promote information sharing and collaboration, information validity and source verification is of major concern. Therefore, users will have varying privileges based on their roles within the health care community in St. Lawrence County. Three

user groups were identified — visitors, public users, and health providers. Each will be discussed in detail in following sections.

(4) **Low Maintenance.** The system, once established, should require as little maintenance and administrative intervention as possible.

The following section will present the features of the prototype system, *NNYHIS*, and discuss the development process. Rapid prototyping was used as the design methodology as it provided for almost immediate evaluation and feedback.

THE NORTHERN NEW YORK HEALTH INFORMATION NETWORK (NNYHIS)

The Northern New York Health Information Network (*NNYHIS*) prototype was established utilizing an IBM RS/6000 550 server running AIX 3.2, an IBM adaptation of the UNIX operating system. UNIX command scripts were used as a high level programming language in the development of the prototype. Like other operating systems, UNIX is a control program for computers. It is designed as an interactive multi-user and multi-task operating system, making it a well suited platform for networking [1]. In addition, several free packages and tools available on the Internet have been extensively used for implementation of sub-domain functions.

FreePort, the software to organize a freenet [13], was evaluated as an alternative to implement the health information network. In many respects, the *NNYHIS* prototype, described in the following sections, provides functions similar to Freenet systems. However, there are several reasons that FreePort was not applied for the development. First, it requires a dedicated server. Second, it is dependent on BSD UNIX 4.3 features, and, therefore it cannot run on an AIX system. At this stage of development, we want to take advantage of the existing resources and expertise at the University and on the Internet. Additionally, because we wanted to develop a highly functional system — extendable as new technology becomes available at low cost — development of our own system provides more flexibility and alternatives.

An Overview

The *NNYHIS* prototype is organized as an electronic building. From text-based menus, users can access services based on the privileges they have. Services not available to a particular user are eliminated from the menu. There are three types of users — *visitors*, *public users*, and *health care providers*. A **visitor** can log into the system without a password and read the news and public discussion forum, use the “Information Gateway” to connect to other systems on the Internet, and transfer files from the visitor’s working directory on *NNYHIS* to their local disks. However, to ensure

security a visitor cannot use the “Post Office”, i.e. electronic mail services, or post messages on the system. To use these services, a user must be registered in the system and have a valid account either as a **public user** or **health care provider**. While these users have similar privileges, only health care providers have access to the “Provider Center”, where they can read and write to a discussion forum reserved only for certified health care providers.

Users with Internet access can utilize Telnet, the Internet’s remote control protocol, to remotely access *NNYHIS*. Users with no Internet access are provided with an installation file, an auto-dial-up file, and all necessary files for Kermit terminal installation, allowing them to access via their modem. File transfer programs are provided to help a new user install a client workstation and connect to *NNYHIS*, using a standard modem and phone line. The auto-dial-in file sets up the modem configuration parameters, dials the access number, and connects with the University’s campus network system. Once connected, it remotely logs the user into a **visitor** account, requiring no password. Users can also use commercial communication software, which typically include a phone list utility.

User Identification and Account Application

The system administrator is responsible for determining user privileges when setting up accounts. The auto-dial-in file automatically logs a user in as a visitor. The user then has an option to login as a registered user, continue as a visitor, or apply for a new account. Obtaining a new account requires finishing an online application, which includes user information, and identification of a unique userid and password. Additionally, a signed statement, detailing the purposes of the account, must be received by mail before the system administrator completes registration of the user. If the account is approved, the identifying registration information is appended to the system user profile. For security purposes, *NNYHIS* has been designed to recognize the group a user belongs to, and provide only relevant menus and corresponding services.

Menus and On-Line Help

All menus in *NNYHIS* are in plain text, with numbered options to access submenus or carry out a service function. Users can get help from several different sources. They can access the Help Desk located in the Information Center (from the main menu) for a general system use description. They can also choose ‘h’ from the menu they are currently viewing to get context specific help. Additionally, the system provides a choice of ‘About.’, in which documentation about the current service area is displayed. Finally, a user can e-mail the system administrator with further questions or

Figure 1
Opening Screen — Provider

```

NN  N  NN  N  Y  Y  H  H  II  SSSS
NN  N  NN  N  Y  Y  H  H  II  S
N  N  N  N  N  N  Y  HHHHHH  II  SSS
N  NN  N  NN  -Y  H  H  II  S
N  N  N  N  Y  H  H  II  SSSS
    
```

Brought to you by:
Public Health of St. Lawrence County &
Department of MIS and Marketing at Clarkson University

Dial-up Number: (315) 268-4400
IP Address: craft.camp.clarkson.edu (128.153.16.6)

Welcome To Northern New York Health Information System!
Please read the information about this system in Information Center
before you for the first time use this system.

You logged in NNYHIS as a health-care provider. As a provider you have
privileges to view all news, participate all discussion forums, use
e-mail system and file transfer services, etc. You should also be
responsible to all information you provide. Thank you for your support.
Last login: Dec 09 11:49 from (som320z7.som.cla)
End of file, press ENTER to continue ...

16 31

Figure 2
Main Menu — Provider

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NN  N  NN  N  Y  Y  H  H  II  SSSS
NN  N  NN  N  Y  Y  H  H  II  S
N  N  N  N  N  N  Y  HHHHHH  II  SSS
N  NN  N  NN  Y  H  H  II  S
N  N  N  N  Y  H  H  II  SSSS
    
```

***** PROVIDER MAIN MENU *****

1. About NNYHIS
2. Information Center
3. Post Office
4. Public Center
5. Health Provider Center
6. Information Gateway
7. File Services

h - help information m - Main Menu
! - escape to shell u - previous menu

q - exit NNYHIS system

Your choice ==>

16:31

comments. The initialization screens of visitors, public users, and health care providers briefly describe *NNYHIS* and the privileges available to the appropriate user group. Figure 1 is an example of the opening screen for **health care providers**.

Following this screen, news headlines and daily agenda items are displayed. The main menu for the user group is then displayed. Figure 2 displays the options available to **health care providers**.

As noted earlier, services not available to a particular user group are eliminated from the menu. For example, the main menu for a **visitor**, shown in Figure 3, does not include options for the Post Office (electronic mail services) or the Health Provider Center (discussion forum).

A text-based menu system was chosen to allow low-cost access to a user with 286 PC and an EGA monitor. The menu structure adapts a wide-and-shallow pattern, with the depth of menus limited to three levels, found to be the preferred number based on several empirical studies [38].

Services

Electronic Mail System

When a registered user elects to use the mail service to check for new mail or review old mail, a mail message screen is brought up if the folder is not empty. Otherwise a message is displayed indicating that "You have no mail". Through the menu service on the bottom of the screen, the user can reply to mail, send an individual or group message,

delete, forward or save the current mailing.

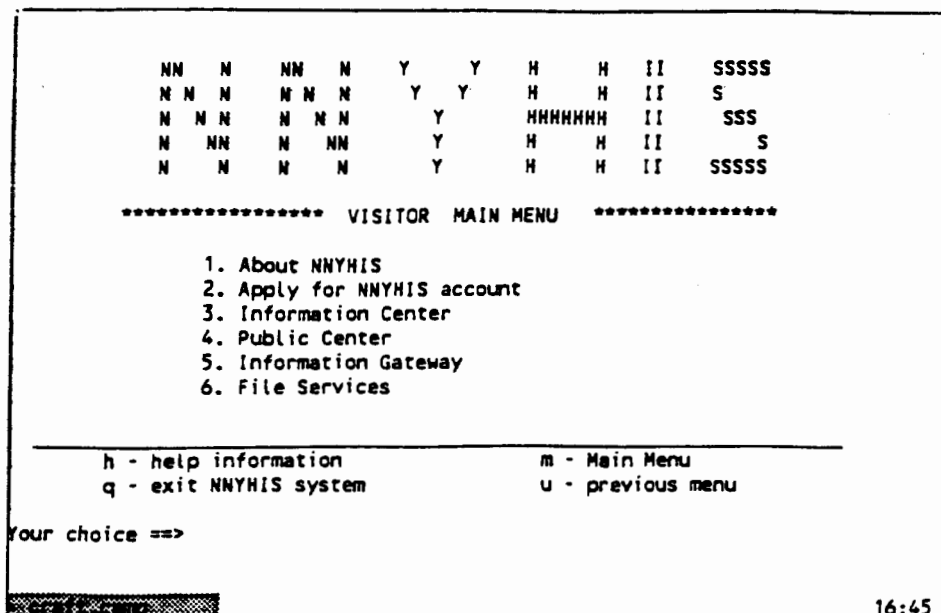
A useful feature is the **alias utility** in which a user can abstract the return address of the current message into an individual alias. A single alias name can also be used to represent a group of people by establishing a group alias. In this way, for example, the County Public Health Department can mail to a chosen group conveniently and efficiently. An additional feature, useful for a more advanced user, is customization by the user of their mailer configuration, such as the editor used to write a mail message.

NNYHIS uses Elm Mail System Version 2.4, an interactive screen-oriented mailer system, to provide the electronic mail services. Elm incorporates enhanced features of several UNIX mailer systems, e.g. Berkeley Mail and Mailx. It was chosen because it provides users flexibility to configure their individual environment according to their needs and skill level. A default setting, for each type of user group, has been established.

Bulletin Board System

The BBS was identified as a major priority by the Department of Public Health. Installing a BBS facilitates the Public Health Department's role as gatherer and disseminator of information of interest. Reliance on sending messages via FAX or the mail is time consuming, costly, and generally problematic. The BBS allows for immediate posting of messages — interested parties regularly using the system would be assured of timely information. For example, an

Figure 3
Main Menu — Visitor



important responsibility of the Public Health Department is to gather disease outbreak data, interpret the data, and make timely (sometimes urgent) general announcements.

The BBS provides three services: a news broadcasting board, a public discussion forum, and a providers-only discussion forum. The BBS demonstrates that a system can be set up for particular user groups with differing privileges. The news broadcasting notes file is configured as read only for all users, except news Directors. Similarly, the discussion forums are set to read/write as a function of the user group.

When a BBS message is opened, all current, unread message headers are listed on the screen. All registered users are allowed to read and write to the public discussion forum, while visitors can only browse what is going on in the discussion. Only providers can read and write to the provider's discussion forum. With read rights, a user can save a message on the BBS to a file in their working directory.

The UNIX notesfile system, available on the University computer system and developed at the University of Illinois [9], was used to implement the bulletin board system (BBS). It coordinates access to and updates databases of notes and their responses. Separate notesfiles contain discussions on separate subject matters. Similar to the protection scheme of UNIX file system, a Director of a 'note subject' can set access rights, i.e. none, read only, read and answer, read and write, write only, or answer only.

Interface to Other Internet Resources

Currently, an Internet Gopher client system can be linked as the file retrieval system [22]. A Health Information Gopher server has been installed on the University campus network, and is being integrated into *NNYHIS*. Through Gopher, users can search by keywords for information and connect to other systems, such as electronic libraries, on the Internet. Users can save their search to a file in their working directory, or download the file to their local disk on their PC. Both a Gopher server and client are installed in *NNYHIS*. The Gopher server, managed locally, provides a means to distribute text documents produced locally or to provide direct links to text documents stored on other Gophers which may be of interest locally. A user accesses Gopher resources through the client which connects to the local server by default but can access any other Gopher server in the world.

File Services

Each user has a working directory on the host, where they can temporarily store files saved from the mail system, bulletin board, or Gopher. For dial-up users, *NNYHIS* supports Kermit protocol to transfer files between the working directory on the server and the local drive on a client PC. Although a comparatively slow protocol, it is extensively used in several public domains and is noted for its transmission accuracy over noisy phone lines. For users with Internet access, *NNYHIS* also provides FTP, a file transfer protocol

that will allow the user to transfer the file via the Internet.

CONCLUSION

The *NNYHIS* prototype meets the expressed needs and priorities of the St. Lawrence County Department of Health. *NNYHIS* (by utilizing existing resources and expertise at Clarkson University, and free packages and tools on the Internet) provides an easy to use front-end interface to community computing services. *NNYHIS* demonstrates the feasibility and value of a low cost computer-based infrastructure to facilitate information and knowledge sharing. A robust solution has been developed that allows for a minimization of the cost of implementation by using low cost technology. Anyone owning or with access to a 286 PC can gain easy access to the system by purchasing an inexpensive connection kit.

By all indications the 1990's will continue to see an accelerating awareness-of and access-to wide area networks. At this point it is not clear if the Internet, the proposed NREN, or some other future network will be the "information highway" of the future. What does seem clear however is that the saturation of personal computers into both corporate and home environments, combined with increasing user awareness of the possibilities of network-based virtual communities, provide strong indications that this technological infrastructure represents dramatically new possibilities for the dissemination and sharing of information among healthcare organizations and other interested stakeholders.

NNYHIS demonstrates how healthcare organizations can utilize this emerging trend in telecommunications to create a new form of electronic gathering place in which public health organizations, healthcare providers and other interested parties can "meet" electronically. The ability to provide this service in a low-cost, easy to use manner is crucial if this technology is to be widely adopted. While it is a challenge to build a system with such a diverse client base — where ease-of-use, low-cost and security are of highest priority — *NNYHIS* demonstrates one way in which such a system can be built now using proven technology.

At the same time, not all the unknowns surrounding this type of system are purely technical. There is much to be learned about the evolution of patterns of usage in such a system. The concept of a virtual healthcare community is very new and a longitudinal study of user acceptance and adoption of such systems is clearly needed. That is the planned next phase of the *NNYHIS* project. Data from that phase should indicate the difficulties and obstacles which healthcare organizations face if they are to take advantage of one of the most potentially significant emerging trends in telecommunications for the 1990's: the increasing availability of easy-to-use, low cost, wide area communication networks.

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