

**Final Technical Report on DOE Awards
DE-FG06-94ER61918 and DE-FG03-94ER61918
to Oregon Health Sciences University**

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Introduction

This final technical report covers the activities of four grants funded by the U.S. Department of Energy between September 15, 1994 and September 29, 1999 (DOE grants DE-FG06-94ER61918 and DE-FG03-94ER61918). For the sake of simplicity in this report, the four grants will be referred to as:

DOE 1:

Title of Project: Models of an Advanced Information Communication Research Network for Regional Health and Environmental Research

Project Period: September 15, 1994 - September 29, 1995

DOE 2:

Title of Project: Prototype Network and Program Support for Regional Outreach and Outcomes Activities

Project Period: September 30, 1995 - September 29, 1996

DOE 3:

Title of Project: Multi-user, Patient-centered Health Care Network Transaction Systems Development and Community Trials

Project Period: September 30, 1996 - September 29, 1997

DOE 4:

Title of Project: The OHSU Digital Capstone Project

Project Period: September 30, 1997 - September 29, 1999

The activities at Oregon Health Sciences University funded by these DOE grants fall into four major areas: information technology, information services and support, medical informatics and outcomes research, and collaboration with other institutions; and are organized in this way in this report, with subsections for groupings of similar activities.

1. Information Technology
 - A. Information Technology Infrastructure and Equipment to Support Health Care Information Access
 - B. Regional Health Care Information Network
 - C. Technical Support for Health Care Information Network
2. Information Services and Support
 - A. Library Infrastructure, Equipment and Databases to Enable Access to Health Care Information
 - B. Patient Resource Center
 - C. Educational Communications Infrastructure and Equipment to Facilitate On-site and Distance Learning
 - D. Web-based Distance Learning
 - E. Digital History Project

3. Research in Medical Informatics and Outcomes Research
 - A. Medical Informatics
 - B. Outcomes Research
4. Collaboration with Other Institutions
 - A. OHSU Collaboration with Oregon Graduate Institute
 - B. Oregon Primate Center Informatics Platform Development

Background

Oregon Health Sciences University is the only academic medical center in the state, with a four-part mission of high-quality health care, education, research and outreach. The university includes schools of medicine, nursing and dentistry; a hospital, children's hospital, and outpatient clinics; research institutes; and several outreach and public services units. A non-profit public corporation, OHSU has a central campus on Marquam Hill in Portland, but its programs and services extend throughout the state, giving it a 96,000-square-mile mission and campus.

The Biomedical Information Communication Center (BICC) is a collaborative program at OHSU that integrates the information technology, information services and support, and medical informatics and outcomes research activities at the university. It has been predominantly the units at the BICC that have conducted the activities funded by the DOE grants as the university has worked to establish a regional health care information and research network.

SECTION ONE: Information Technology

A. Information Technology Infrastructure and Equipment to Support Health Care Information Access (Supported by DOE 1, DOE 2, DOE 3, and DOE 4)

To create access to electronic health care information that can be used by OHSU's researchers, health care providers and educators as well as those outside the university, improvement in the information technology infrastructure was critical. Funding from all four DOE grants contributed to the purchase, installation and implementation of an extensive array of computing resources and an integrated network of over 7,000 workstations throughout the university system, both on campus and off. The Information Technology Group (ITG) is the unit at OHSU responsible for implementation and management of information technology and had oversight of the activities conducted with this portion of the awards.

In the past five years ITG has implemented the OHSU Workstation, a standard desktop used on both PCs and Macintosh computers throughout the university to support research, education and patient care. Core services on the workstation include electronic mail; word processing, spreadsheet, presentation and database software; bibliographic

databases; patient care systems; accounting systems; the human resources system; access to Internet browsers; and virus protection.

With DOE funding ITG has installed an asynchronous transfer mode – 622 MBPS backbone to allow connectivity between OHSU sites both on and off campus and outreach sites. Appendix A is a diagram of the current OHSU Network showing the numerous servers on campus that are connected to the network as well as connections to OHSU remote sites and other outreach connections.

B. Regional Health Care Information Network (Supported by DOE 1, DOE 2, DOE 3, and DOE 4)

As part of the DOE awards, OHSU has been able to purchase, install and implement the necessary infrastructure and equipment to create links to other clinical sites throughout the state to allow the transmission of health care information.

With the expansion of OHSU primary care clinics throughout the northwestern area of Oregon, OHSU has created a greater access to health care to the citizens of the state. Clinics in SW Portland, SE Portland, Beaverton, Tigard, Hillsboro, Scappoose, and Oregon City are networked to OHSU and have the same access to the services of the OHSU Workstation as PCs on campus.

Beyond the university OHSU has established outreach links with Grande Ronde Hospital in LaGrande in eastern Oregon, the Asante Health Systems in Medford in southern Oregon, and the Merle-West Medical Center in Klamath Falls in southeastern Oregon. Additional links include the Multnomah County Health System, the Kaiser Permanente NorthWest system, Portland Public Schools, the Oregon Regional Primate Research, ODS Health Plans, and Regence Blue Cross/Blue Shield.

In addition, individual health care professionals throughout Oregon can have access to health care information through OHSU via modem access or through the Internet.

The creation of the Lifetime Clinical Record, with some funding provided through DOE 1, enhances the regional health care information network by allowing access to OHSU's electronic medical record by appropriate clinical staff throughout the OHSU system. Thus a physician at the OHSU clinic in Scappoose, Oregon can access a patient's record as can someone at the Beaverton clinic or at the Portland campus.

C. Technical Support for Health Care Information Network (Supported by DOE 2, DOE 3, and DOE 4)

An important aspect of the regional health care information network is the technical support OHSU has provided for its own staff as well as others connected throughout the state. From a two-person technology support system for the OHSU Hospital in the early 1990s, the OHSU Help Desk has evolved into a 16-person team that supports the entire

OHSU system, both on campus and throughout the state with the technical support needed to carry on the OHSU mission of healing, teaching, discovery and outreach.

When the Hospital Information System support was expanded in 1994 to include support for the OHSU network and all workstations and supported information services at the university, the support unit was dubbed The Bridge, a visualization of the unit's role of connecting users with the information they sought. After several years, as the Bridge staff expanded, it was renamed the Help Desk, a term more familiar to a variety of users as an information technology support unit.

The support from the four DOE grants has enabled this expansion of the Help Desk through the implementation of equipment and databases and staff expansion. As OHSU has expanded its information technology outreach throughout the state to establish a regional health care information network, the Help Desk has played a vital role in support to users throughout OHSU's 96,000-square-mile campus.

SECTION TWO: Information Services and Support

A. Library Infrastructure, Equipment, and Databases to Enable Access to Health Care Information (Supported by DOE 2, DOE 3, and DOE 4)

With assistance from the DOE grants, the OHSU Library now has both physical and virtual areas in which to provide access health care information. An area in the Main Library in the BICC houses both PCs and Macintosh computers to allow faculty, staff and students full access to the services and applications of the OHSU Workstation. As the only academic health sciences library in Oregon, the OHSU Library also offers the public access to health care information. Anyone is welcome to use workstations in the Library for access to databases such as MEDLINE and Health Reference Center.

Electronic access to health care is available through the Library's Web pages on the Internet or by Telnet access. With the growth of the World Wide Web in the last several years, the OHSU Library has used part of the DOE awards for development of Web pages with extensive links to both OHSU health information resources and those throughout the Web. The OHSU Library online catalog, bibliographic databases such as MEDLINE and CINAHL, and the full text of leading medical and nursing journals can all be accessed by OHSU faculty, staff and students and registered Oregon health professionals, no matter where they are. Between OHSU and PORTALS (Portland Area Library System), access to 30 health care and academic databases is available. This is another facet of the regional health care information network that has been established as part of the four DOE projects.

In addition, DOE funds were used to provide additional equipment for the Design Lab, housed in the OHSU Library. The Lab provides access for the OHSU community to computing resources and the space to create professional slide presentations, brochures, reports, posters and Web pages.

B. Patient Resource Center (Supported by DOE 2, DOE 3, and DOE 4)

With funding from three DOE awards, the OHSU Library created the Consumer Health Resource Center, which has the objectives of enabling both health care professionals and lay people to access patient education materials. Margaret Connors, MLS, MSW, was hired as the first Health Resource Coordinator in 1995. Since 1998, Dolores Zegar Judkins, MLS, has been Health Resource Center.

While plans were formulated to create a physical Health Resource Center in a high-traffic area of the OHSU Hospital, the OHSU Library has added a number of consumer health books and newsletters to its collection. With renovation of the main reception area of the Hospital in the last year, the Health Information Library is slated to open there in December 1999.

The Health Resource Center provides electronic access to health information, too. The increasing growth and use of the World Wide Web has led to development of special links to consumer health information within the OHSU Library Web site. The pages include:

<http://www.ohsu.edu/biccLibrary/consumerhealth/index.shtml>
<http://www.ohsu.edu/bicc-Library/consumerhealth/him.shtml>
<http://www.ohsu.edu/bicc-Library/consumerhealth/children.html>
<http://www.ohsu.edu/bicc-Library/consumerhealth/chlinks.html>
<http://www.ohsu.edu/bicc-Library/patiented/>

One of the Web pages provides links to a large number of patient education materials in Spanish. Ms. Connors published a paper about these Web-based Spanish language resources in Medicine on the Net (see Bibliography).

The Health Resource Coordinator has conducted a number of workshops, some for non-medical librarians and some for lay people, on using the OHSU Web pages to find health information and others for health practitioners on finding information for patients. In February 1999, Ms. Judkins gave a presentation on "The Internet Prescription for Health Information" at the Online Northwest '99 conference.

A special service titled Health Information by Mail began in 1997. Anyone can call the Health Resource Center to request basic health information in non-technical language. Information is mailed to the patron at the person's residence. Over 800 questions have been answered through the HIM service with all returned evaluations stating that the information helped with their health problem.

**C. Educational Communications Infrastructure and Equipment to Facilitate
On-site and Distance Learning
(Supported by DOE 2, DOE 3, and DOE 4)**

In the mid-1990s the OHSU School of Nursing in Portland assumed administrative responsibility for nursing programs in three other locations in Oregon: Eastern Oregon University in LaGrande, Oregon Institute of Technology in Klamath Falls, and Southern Oregon University in Ashland. Now with a four-campus program, the use of distance learning technologies has been essential. Funding through the DOE grants has been used to equip rooms in the School of Nursing building and the Biomedical Information Communication Center to provide state-of-the-art videoconferencing capabilities. The Educational Communications department in the BICC provides the technical support and maintenance of these areas.

Not only does the distance learning equipment at OHSU in Portland allow interactive classes with the other three nursing campuses, but the RN/BS Outreach Program, the Rural Frontier Delivery Program, and the Outreach Graduate Education Program use distance learning technologies to broadcast to receiving sites throughout the state where students do not have to travel to a distant campus to participate.

Other areas on campus were also equipped with digital upgrades so that OHSU faculty could use a multi-media approach to instruction. A number of classrooms in the Basic Sciences Building, Old Library Building, and School of Dentistry have been equipped with data projectors, VCRs and monitors, phone and network jacks and teleconferencing equipment.

**D. Web-based Distance Learning
(Supported by DOE 4)**

The Virtual Learning Center was a research and development activity built into the OHSU Web Lab. As a prototype project in DOE 4, the purpose was to create a Web-based authoring system to be used and tested by the School of Nursing for distance learning. Development of the application began in 1997; the goals were to develop and test a distance learning tool that allowed faculty to publish, edit and manage online courses that were easy for students to navigate and to allow students and faculty to communicate both synchronously and asynchronously. After a year of development, several nursing courses were mounted and tested during the 1998-99 academic year.

While the tests proved the concept of the Virtual Learning Center, it was not possible to provide support to the level the faculty preferred. Consequently, the School of Nursing has decided to work with the other Oregon higher education institutions to move courses to e-College, a commercial provider.

Evaluation of the Virtual Learning Center found that:

- 1) Students and faculty need more instructional design support and "help desk" support than anticipated, certainly more than the R&D effort could provide.

2) The VLC software was designed to accommodate a wide variety of teaching styles, using a very open Web-based authoring structure. This resulted in a dichotomy—low and high structure. In such a circumstance, much more support is needed.

The Web Lab is now being repositioned to be a system-wide R&D facility for the design and use of streaming video. Amy Wilcox, Andrea Ball, MLS, and Leslie Cable, MLS, from OHSU gave a presentation on the Virtual Learning Center at the Online Northwest '99 conference in Portland February 12, 1999.

E. Digital History Project (Supported by DOE 4)

This pilot project laid the groundwork for the use of the digital medium to capture the past. Joan Ash, PhD, MLS, served as principal investigator of the Digital History Project, whose purpose was to document the history of Oregon Health Sciences University using audio and video recordings of interviews conducted by professional trained oral historians and to create digital transcripts and photographs to preserve the information in digital form. Interviewees included faculty, staff and students from all schools and programs at OHSU and selected outside individuals who played critical roles in OHSU's past. Charles T. Morrissey, Oral Historian at Baylor College of Medicine, served as consultant.

Between October 1997 and March 1999, 66 oral history interviews were conducted and recorded on audio or video tape. Interviewees included former Senator Mark O. Hatfield, OHSU President Peter Kohler, former department chairs in the School of Medicine, and others whose affiliation with the university went back as far as 60 years ago.

In 1998, slide, audio and video presentations on the history of OHSU was given by Dr. Ash and Linda Weimer, MS, research associate, to the faculty and staff of the Biomedical Information Communication Center and at the OHSU Employee Recognition Awards. This presentation was also given several times to a School of Medicine class on the humanities in medicine.

Also in 1998 Annette Matthews, an OHSU medical student, used some of the oral history transcripts and additional interviews to research the development of the Starr-Edwards heart valve. Ms. Matthews won the Texas Heart Institute Award for Undergraduate Writing in the History of Cardiovascular Medicine and Surgery for a paper she wrote on this topic.

SECTION THREE: Research in Medical Informatics and Outcomes Research

A. Medical Informatics (Supported by DOE 2, DOE 3, and DOE 4)

Research in medical informatics, the development, dissemination and evaluation of information technology in the health care field, began at OHSU in 1989. In the past 10 years the research program has grown and in 1997 became a separate division within the OHSU School of Medicine, known as the Division of Medical Informatics and Outcomes Research (DMIOR). Currently there are 12 primary faculty with 25 adjunct faculty in the division.

As the division has grown, it has established a Master of Science program in medical informatics, now in its fourth year. A fellowship program from the National Library of Medicine provides postdoctoral training in medical informatics.

Funding from the Department of Energy has allowed investigators to conduct medical informatics research and to develop informatics curricula. Paul Gorman, MD, assistant professor of medical informatics and outcomes research, has conducted assessments of information needs of primary care health providers. Dr. Gorman has tracked the need for health care information by these clinicians arising from interactions and what sources clinicians use to answer these questions. Joan Ash, PhD, MLS, studies diffusion of innovations theory to information technology in health care. She has investigated how the introduction of end user database searching, electronic mail and the electronic medical record have been introduced in academic medical centers.

William R. Hersh, MD, chief of the division, has done research on information retrieval and has also investigated the use of the World Wide Web for the delivery of online information on health care. Christopher Dubay, PhD, a medical geneticist, studies the dissection of the genetic basis using the biostatistical techniques of linkages analysis in model systems and humans.

Some of the resources from the DOE awards were used for the development of the medical informatics curriculum, which is offered through the School of Medicine. Students in the two-year Master of Sciences in Medical Informatics program take these courses in partial fulfillment of their degree. Medical students may also take electives in medical informatics. In addition, DMIOR faculty have used the medical informatics curriculum in an annual two-day continuing medical education course designed for practicing clinicians to introduce them to electronic health care resources.

With funding from DOE 4, DMIOR has begun development of a World Wide Web-based medical informatics curriculum. This program was developed in 1998-99 and pilot-tested in the fall of 1999 with an online course, Introduction to Medical Informatics, taken by 13 students across the country. Plans are underway to develop further online informatics

courses, including a CME course, and offer a certificate in medical informatics for distance learners.

B. Outcomes Research
(Supported by DOE 2, DOE 3, and DOE 4)

One of projects funded by all four DOE grants was the development of an outcomes research unit at OHSU. Outcomes research involves the assessment of health care practices based upon data collected on those practices, in other words, what works and what doesn't work in health care.

Housed in the Division of Medical Informatics and Outcomes Research in the School of Medicine, over the past five years of DOE funding, the unit has grown to include five faculty members, including a statistician, an operations director, three systems analysts, and three research associates/assistants. Mark Helfand, MD, MS, associate professor of medicine and medical informatics and outcome research, serves as director of the outcomes research program.

As the program has grown, investigators have begun to conduct research on a variety of outcomes issues. Mark Helfand, MD, MS, Karen Eden, PhD, and Susan Mahon, MPH, conducted a research project on the exposure of Americans to iodine-131 from nuclear testing in Nevada from 1951 to 1962. This was in collaboration with the Institute of Medicine. They produced a background paper about screening for thyroid cancer to review whether early detection and intervention might be useful for those exposed to nuclear fallout radiation as children in the 1950s.

Using a systematic review approach, the team obtained the relevant literature obtained from a MEDLINE search from 1966 -1998 and included 56 published studies in their review. The research team investigated the probability of developing thyroid cancer, mortality and morbidity of thyroid cancer, screening and confirmatory tests, consequences of screening, and stage and history of cancers in exposed populations. The effectiveness and harms of screening as well as the effect of early detection on mortality were also reviewed.

The investigators found that 32 cancers would be found per 10,000 people screened and that 184 people with thyroid cancer would need to be treated to prevent 1 death in 5 years. Therefore, 1 death would be prevented for every 57,445 individuals screened, but could lead to 26 surgical complications. The investigators also found a 35% false positive rate for fine needle aspiration.

The background paper on screening for thyroid cancer by Drs. Helfand and Eden and Ms. Mahon was published as an appendix in a report released by the Institute of Medicine and the National Research Council. Dr. Eden will present this research to the 6th International Conference on Long-term Complications of Treatment of Children and Adolescents for Cancer in June 2000.

Other research projects conducted by the outcomes research unit, with DOE funding, include statistical consulting by Dale Kraemer, PhD, on analyses of clinical data of patients receiving chemotherapy with blood-brain barrier disruption, analyses of an educational intervention for improvement in the diagnosis of depression, economic assessment of the costs associated with variceal bleeds, development of model to predict Medicare managed care plan enrollees at high risk for adverse health outcomes through use of a self-administered questionnaire, and evaluation of the health outcomes of patients undergoing endoscopic exams for gastroesophageal reflux disease and related conditions. Cynthia Morris, PhD, has conducted population-based studies to evaluate the long-term natural history of congenital heart defects.

Outcomes Research at OHSU also has an Outcomes Service unit, a data management and analysis service that focuses on clinical data. With support from the DOE awards, the Service began operations in 1997. A development group in the Outcomes Service is implementing the OHSU Clinical Outcomes Database by integrating clinical data from multiple sources into a comprehensive database. This project involved formatting the data, cleaning it; creating meaningful links between the data sets, collecting missing information, and documenting information about the source, quality and use of the data.

Currently the Outcomes Database (also known as the data warehouse) contains data on patient accounting, outpatient billing, ICD9 diagnosis, inpatient census, case insurance coverage, referrals, patient demographics, laboratory results, DRG for inpatient admissions, certain MHO enrollment and claims data.

A pilot project on diabetes registry and tracking will use the Outcomes Database for such applications as chart summary of preventive exams, quarterly reminders to the primary care physician of diabetics who need exams, and annual provider and clinic statistics of diabetic care performance. This project is currently in pilot operation at the OHSU Gabriel Park Clinic is southwest Portland. Other applications of the database have included a trauma utilization study and a DRG 209 performance improvement report.

The Outcomes Service also writes clinical applications for specialty groups, develops data entry forms, and provides consultation on topics such as statistical risk adjustment, predicting utilization and health outcomes, and performance measures. Services related to creation of survey forms and analysis of the collected data include reporting and analysis support for clinical quality improvement efforts of the OHSU Practice Parameter Program, an internal patient survey project for OHSU Quality Management, Wellness Profiles for Occupational Health, and a senior general health survey for the Oregon Health Plan Office.

A patient satisfaction survey for the Integrated Primary Care Organization has been developed and tested and will be administered on a biannual basis to participating OHSU primary care clinics. Its primary goal is to identify and evaluate patient satisfaction and to provide clinic managers and health care providers with information that can be used to evaluate and effectively improve patient care.

SECTION FOUR: Collaboration with Other Institutions

A. OHSU Collaboration with Oregon Graduate Institute (Supported by DOE 3)

With support from DOE resources, Oregon Health Sciences University and the Oregon Graduate Institute of Science and Technology (OGI) collaborated on a pilot project to use information technology to deliver collaborative health care. The research team, led by Holly B. Jimison, PhD of OHSU and Michael Pavel, PhD, of OGI, included William Hersh, MD, Paul Gorman, MD, and Paul Phillip Sher, MD, of OHSU. Lois Delcambre, PhD, Todd Leen, PhD, David Maier, PhD, and Jonathan Walpole, PhD, of OGI also served as project investigators.

During the one-year project the investigators created a model for a system that would use information technologies to enhance delivery of cost-effectiveness health care in home and assisted-living situations. In the CARE system (Coordinated, Accessible, Relevant, Effective) model, an "information bus" would serve as a bridge between electronic health care resources, such as a Web server or bibliographic databases, and the users of the resources. Such users could include primary care physicians, specialists, nurses, social workers, physical therapists, case managers, and the patient himself. The CARE model proposed a variety of communication capabilities, tailored to the user of the health care resources: electronic mail, voice mail, video conferencing, Web sites, etc.

An outcome of this collaborative project was further research on how those who coordinate care use information resources. Paul Gorman, MD, along with Patricia Patterson, PhD, RN, and Mary Lavelle, RN, MS, conducted a survey of case managers. Dr. Patterson presented this research at the American Medical Informatics spring meeting in 1998. Dr. Gorman and Ms. Lavelle did a similar research project, conducting extensive interviews with case managers in Oregon and found that they are constantly updating their personal information base and cross institutional/programmatic boundaries to "do whatever needs to be done" for the benefit of elders. Ms. Lavelle presented this research at the 4th Internal Conference on Long Term Care Case Management in December 1998.

Another focus that came out of the collaborative care project was the use of videoconferencing in the nursing home setting. Dr. Patterson is doing research on this topic, and Dr. Gorman chaired the master's thesis committee of a medical informatics student, Saraswathi Raman, MD, whose thesis was on assessing the benefits of videophone technology in internal medicine.

B. Oregon Primate Center Informatics Platform Development (Supported by DOE 2, DOE 3, and DOE 4)

The Oregon Regional Primate Research Center was founded in 1962 and is now considered an institute at OHSU. As one of seven such centers, it conducts basic and applied biomedical research in areas such as neural development and degeneration,

factors involved in all stages of reproduction, and host-virus interactions. The Beaverton, Oregon campus of the Center is approximately 15 miles from OHSU and has four major research buildings.

As part of DOE 4, network infrastructure and equipment was installed at the Primate Center to link the Center to OHSU and the Internet by providing the Center with state-of-the art communications access. The funding provided Professional Data Exchange consulting, programming services, and computing equipment. In addition, a Polycom view station was purchased to bring teleconferencing capabilities to the Primate Center. Adding this connectivity to the Primate Center was another step in establishing the regional health care information network.

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OHSU Network

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