National Center for Research Resources
NATIONAL INSTITUTES OF HEALTH

Supporting Connectivity for Biomedical Research Executive Session

Crystal Gateway Marriott Hotel, Arlington, VA

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Final Workshop Report

September 2006

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ABBREVIATIONS USED

AHIC	American Health Information Community
AHRQ	Agency for Healthcare Research and Quality
BIRN	Biomedical Informatics Research Network
BISTI	Biomedical Information Science and Technology Initiative
caBIG	Cancer Bioinformatics Grid
CERMUSA	Center of Excellence for Remote and Medically Underserved Areas
CIO	Chief Information Officer
CI-TEAM	Cyberinfrastructure Training, Education, Advancement, & Mentoring
EHR	Electronic Health Record
ePCRN	Electronic Primary Care Research Network
HDC	Health Disparities Collaboratives
HRSA	Health Resources and Services Administration
IDeA	Institutional Development Award
IHS	Indian Health Service
INBRE	IDeA Networks of Biomedical Research Excellence
IP	Internet protocol
ISP	Internet service provider
IT	Information technology
LEARN	Lonestar Education and Research Network
MHS	Military Healthcare System
MIDAS	Modeling of Infectious Disease Agent Study
NCBC	National Centers for Biomedical Computing
NCMHD	National Center for Minority Health and Health Disparities
NCRR	National Center for Research Resources
NECTAR	National Electronic Clinical Trials and Reporting
NEON	National Ecological Observatory Network
NIGMS	National Institute of General Medical Sciences
NIH	National Institutes of Health
NITRD	Networking and Information Technology Research and Development
NLM	National Library of Medicine
NLR	National Lambda Rail
NMR	Nuclear magnetic resonance
NSF	National Science Foundation
PBRN	Primary Care Practice-Based Research Networks
RCMI	Research Centers in Minority Institutions
REN	Research and education network
RON	Regional optical network
RPMS	Resource and Patient Management System
SURA	Southeastern Universities Research Association
TATRC	Telemedicine and Advanced Technology Research Center
TX	Transit exchange
VHA	Veterans Health Administration

II. EXECUTIVE SUMMARY

High-speed computer networks are vital to biomedical research, yet the infrastructure supporting network connectivity remains unevenly distributed. This workshop joined together biomedical researchers, networking experts, and computer scientists from across the country to identify key challenges to improving network connectivity and utilization across a broad spectrum of users, including those with ready access to cutting-edge networks and those with little or no connectivity.

Among the more than 80 participants, approximately 40% were academic investigators in the basic life sciences, clinical and translational research, and ambulatory health care practice-based research networks. Roughly a third of participants were computer scientists and networking experts from academe and the computer and telecommunications industries. The remaining quarter of participants came from Federal science and health care funding agencies including NIH (NCRR, NLM, NIGMS, and NCMHD), NSF, TATRC, VHA, and HRSA.

A draft white paper developed by NCRR, TATRC, and Internet2 staff with help from experts in relevant fields was circulated to participants prior to the workshop to frame discussions at the executive session. The charge to the group at the executive session was to identify key needs and priorities for cyberinfrastructure development during the next three to five years and to examine best practices for implementing collaborative networks driven by research opportunities across the health research spectrum.

The workshop sought to encourage efforts to strengthen partnerships among funding agencies, academic organizations, and the private sector to better coordinate, expand, and optimize investments in network infrastructure. In particular, the workshop highlighted opportunities in systems biology research and the need to leverage natural intersections between health research and health care in order to broaden community participation and facilitate development of clinical and translational research networks.

The workshop began with presentations from NIH- and TATRC-supported researchers illustrating the range of ambitious programs that can be implemented through the formation of appropriately provisioned networks. The presentations outlined key challenges and lessons learned and focused on best practices emerging across a broad cross-section of health-related research applications.

LESSONS LEARNED FROM COLLABORATIVE NETWORKS

- **Connectivity involves people (communities of practice), projects, and software along with network fiber and associated hardware.**
- **Connectivity serves multiple purposes, so plan accordingly to foster:**
    - **Research (*especially* interdisciplinary research)**
    - **Education and research training**
    - **Public service, e.g., improvements in health care delivery**

PRIORITY RECOMMENDATIONS

- **Strengthen communication and coordination between federal funding agencies, academic groups, and public and private sector entities engaged in cyberinfrastructure and telecommunications network development.**

- **Exploit existing government-wide forums to promote interagency collaboration and innovation in the cyberinfrastructure arena, e.g.,**
    - Networking and Information Technology Research and Development (NITRD) Coordinating Groups
    - American Health Information Community (AHIC)
    - Interagency Health Information Technology Policy Council

- **Increase support for software engineering and maintenance to enable collaborative sharing of data and tools on a production scale.**

- **Increase support for IT personnel recurring costs.**
    - Professional project management: bridging the scientific disciplines
    - Operational project management: performance sites and data

- **Nurture a culture of collaboration within and between academic health centers to foster interdisciplinary team science.**
    - Based on large-scale, complex driving research challenges
    - Emphasizing communication and data sharing across disciplines
    - Enhancing academic rewards to recognize and encourage collaboration

- **Close wide gaps in connectivity for minority-serving institutions, developing academic institutions, and hospitals and community health centers in rural and urban underserved areas.**

- **Enhance connections to communities and health care providers.**
    - For community-based clinical and translational research
    - For health care quality, safety, and effectiveness research
    - For health information dissemination to promote healthy behaviors, broaden participation in and better inform academic research, and increase situational awareness (e.g., biosurveillance, population health)

- **Develop network performance measurement tools and an inventory of cyberinfrastructure resources and network connections.**
    - Common performance standards based on end-user experience
    - First-mile connectivity atlas; state-by-state visualization of resources
    - Decision support tools for getting connected (e.g., LAN/WAN cookbook)
    - Bandwidth and quality-of-service requirements for different types of tasks

- **Support planning grants to foster the development of collaborative research partnerships spanning the entire health science spectrum.**

III. WORKSHOP PURPOSE AND OBJECTIVES

SPONSORS

National Center for Research Resources (NCRR)
http://www.ncrr.nih.gov

NCRR, a component of the National Institutes of Health (NIH), provides laboratory scientists and clinical researchers with the environments and tools they need to understand, detect, treat, and prevent a wide range of diseases. This support enables discoveries that begin at a molecular and cellular level, move to animal-based studies, and then are translated to patient-oriented clinical research, resulting in cures and treatments for both common and rare diseases. NCRR connects researchers with one another, as well as with patients and communities across the Nation, to harness the power of shared resources and research.

U.S. Army Telemedicine and Advanced Technology Research Center (TATRC)
http://www.tatrc.org/

The Telemedicine and Advanced Technology Research Center (TATRC), a subordinate element of the United States Army Research and Materiel Command (USAMRMC), is charged with managing core Research Development Test and Evaluation (RDT&E) and congressionally mandated projects in telemedicine and advanced medical technologies. To support its research and development efforts, TATRC maintains a productive mix of partnerships with federal, academic, and commercial organizations. TATRC also provides short duration, technical support (as directed) to federal and defense agencies; develops, evaluates, and demonstrates new technologies and concepts; and conducts market surveillance with a focus on leveraging emerging technologies in healthcare and healthcare support. Ultimately, TATRC's activities strive to make medical care and services more accessible to soldiers, sailors, marines, and airmen; reduce costs, and enhance the overall quality of military healthcare.

The workshop was held in conjunction with the Internet2 Spring 2006 Member Meeting
http://www.internet2.edu/about/

Internet2 is a consortium being led by 207 universities working in partnership with industry and government to develop and deploy advanced network applications and technologies, accelerating the creation of tomorrow's Internet. Internet2 is recreating the partnership among academia, industry and government that fostered today´s Internet in its infancy. The primary goals of Internet2 are to create a leading edge network capability for the national research community, enable revolutionary Internet applications, and ensure the rapid transfer of new network services and applications to the broader Internet community.

PURPOSE AND OBJECTIVES

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A draft white paper, developed by NCRR, TATRC, and Internet2 staff with help from experts in relevant fields, was circulated to participants prior to the workshop to focus discussions and provide a framework for this final report. The charge to the group at the workshop was to identify key needs and priorities for cyberinfrastructure development during the next three to five years and to examine best practices for implementing collaborative research networks. Examples in the following section illustrate the broad spectrum of driving research opportunities in the health and life sciences.

DRIVING RESEARCH OPPORTUNITIES

Basic Biomedical and Behavioral Research

Computer networks underpin virtually all aspects of basic biomedical research, from the capture, storage and analysis of genomic and proteomic data to the visualization of molecules, cells, and organs to the dynamic computational modeling of disease epidemics. Researchers increasingly turn to computing power at the teraflop scale and beyond, using petabyte resources, to enable exciting new applications. But powerful computers alone are not enough to exploit the research opportunities. A comprehensive supporting infrastructure (often termed cyberinfrastructure) must be in place, one that integrates data-gathering facilities, computing hardware, data analysis and informatics tools, interoperable software and middleware, and the expertise needed to develop robust software applications and build, manage, and utilize networks. Network connectivity is increasingly important for interdisciplinary team science because it enables collaborative sharing of valuable data, expertise, and other research resources at optimal rates. Collaborative efforts to develop network infrastructure are therefore of great interest to federal basic science funding agencies and the communities they serve, and to applied research funding agencies as a critical component of public-private partnerships for operational systems such as those envisioned in the HealthGrid.

Clinical and Translational Science

Many clinical research networks operate simultaneously but independent of one another, evaluating vast numbers of therapies, diagnostics, and treatments through rigorous clinical studies. Researchers must sometimes duplicate data from other studies because they are unaware of the data or do not have access to the data. Seamless data sharing across studies would reduce duplication of efforts, leaving more time and funds to address important research questions. Enhancing the efficiency of clinical research networks through informatics and other technologies will broaden the scope of research into preventive, predictive, and personalized medicine as well as community-based participatory and population health research.

Sharing of datasets requires more than just alignment of XML schema; standardized sharing policy and practices (ontology, terminology libraries, data and text mining capabilities) are needed. Toward that end, biomedical informatics research and development is needed to address complex issues such as medication terminology, information security, data storage and access to protocols across a wide area network. Moreover, the new model for clinical and translational science envisioned in the NIH Roadmap for Medical Research (http://nihroadmap.nih.gov/) requires network connectivity that is fast, reliable and secure in order to efficiently manage large, multi-site clinical studies and to rapidly disseminate data to researchers for validation and further study. However, poor connectivity at many academic health centers, physicians' offices, rural hospitals, and community health centers limits their ability to engage in the kinds of integrated research and health care networks that will ultimately be central to translating new knowledge into better community health outcomes.

Overcoming the various barriers to data sharing, which affect virtually all academic medical centers to at least some extent, will greatly expand access to research tools and health information for physicians, patients, and researchers alike, both in academic health centers and in community-based health research settings, including rural or remote locations that rely on wireless technologies.

Health care quality, safety and effectiveness research

The Agency for Healthcare Research and Quality (AHRQ) supports and conducts scientific studies to improve the access, effectiveness, and quality of primary and preventive health care services. One promising approach utilizes primary care practice-based research networks (PBRNs) comprising groups of ambulatory primary care practices, often with affiliated academic or professional organizations, investigating questions relating to community-based practice and patient care. Connectivity extends the scope and reach of PBRNs, bringing evidence-based medical care to more communities and opening new avenues for collaborations with academic researchers to translate knowledge from pre-clinical and clinical studies into improved health outcomes. AHRQ also plays a critical role in the drive to improve health care delivery by advancing the use of health information technology (health IT) in primary care settings. As part of its initiative, AHRQ has funded grants and contracts in 41 states to support and stimulate investment in health IT, especially in rural and underserved areas. These projects constitute a real-world laboratory for examining health IT at work. AHRQ and its partners focus on identifying the challenges of health IT adoption and use, solutions and best practices for making health IT work, and tools that will help hospitals and clinicians successfully incorporate new technologies.

Health Disparities in Underserved Populations

NCRR supports programs to develop biomedical research capacity at minority-serving institutions and at academic institutions in states that historically have not participated fully in NIH-funded research. Owing to their locations and missions, these institutions afford unique opportunities to broaden inclusion of underserved populations in clinical and translational research, both as investigators and as research participants. Efforts to expand research activity at these institutions must address critical needs for better network connectivity. Enhanced connectivity will aid the development of emerging translational research networks focusing on the causes and amelioration of health disparities in underserved populations. Such networks bring together clinician scientists supported by NCRR programs, other NIH-supported clinical research centers, and primary health care providers, including community health centers, to conduct multi-site clinical studies and community-based research designed to speed translation of knowledge into improved community health outcomes. Consortium partners and participating sites require network connectivity for videoconferencing and access to computational tools, shared instrumentation, and a clinical data management system for collecting, storing and analyzing data from multiple sites.

The Health Resources and Services Administration (HRSA) is the principal Federal agency charged with increasing access to health care for those who are medically underserved. HRSA’s portfolio includes a range of programs and initiatives designed to increase access to care, improve quality, and safeguard the health and well-being of the nation’s most vulnerable populations. Much of this work is accomplished through the funding of approximately 940 community health centers comprising nearly 3,600 health center sites that serve 15 million patients each year. As part of its commitment to the national health information technology (health IT) goals, HRSA recently created an Office for Health Information Technology to provide strategic leadership and policy development around health IT as well as to explore opportunities to forge partnerships that result in better health care and health outcomes for the medically underserved.

Similarly, the Indian Health Service (IHS) provides a comprehensive health services delivery system for approximately 1.8 million of the nation’s estimated 4.2 million citizens of American Indian or Alaska Native heritage. The Federal system consists of 33 hospitals, 59 health centers, and 50 health stations. In addition, 34 Urban Indian health projects provide a variety of health and referral services. IHS has long been a national leader in the development and use of electronic clinical information. For over 30 years, IHS and tribally operated health facilities have been using and improving their Resource and Patient Management System (RPMS), a comprehensive electronic healthcare information system composed of over 60 software applications that help streamline health care and evaluate clinical outcomes and processes. Modeled after the electronic medical record used across the Veterans Health Administration (VHA) hospital network, the RPMS electronic health record (EHR) supports a variety of clinical functional components. Advantages include a highly customizable user interface that can be modified to accommodate different information and workflow needs of various users, including biomedical and behavioral researchers.

Public health monitoring, biosurveillance, and situational awareness

The promise of epidemiologic networks to enhance national and global situational awareness is a primary driver for enhanced connectivity. Infectious diseases and their natural vectors defy containment within local or national borders or geographic regions. Timely data collection and analysis and prompt delivery of useful information are critical to the development of effective predictive models to effectively address regional, national or global outbreaks. General recognition of network inadequacy and its impact on economic and health well-being provides an opportunity for federal agencies to address this situation proactively through industry and academic partnerships, focusing, for example, on biosensors networks and correlations between environmental exposures and health status, both in urban and in rural (including agricultural) settings. For instance, the U.S. Army's Telemedicine Advanced Technology Research Center (TATRC) supports research that focuses on the application of advanced technologies to biomedicine. TATRC provides the applied research arm for the Tricare Services and the Military Health System. Programs include the utilization of collaboration grids for human capacity building. Network infrastructure is also a critical component to transparent information workflow between civilian and military sectors, particularly for disaster response scenarios. Technologies developed for meteorology are being leveraged by TATRC’s Situational Awareness Technology Integration Group to develop an infectious disease "weather map."

Interdisciplinary research education and training

Enhanced connectivity at academic institutions strengthens interdisciplinary science education and training programs and furthers the nation’s critical efforts to nurture an inclusive, culturally diverse biomedical research workforce. Toward that end, NCRR’s Institutional Development Award (IDeA) Networks of Biomedical Research Excellence (INBRE) program supports on-line training and education opportunities for students in primarily undergraduate institutions in 22 IDeA-eligible states and Puerto Rico, including historically Black colleges and universities, Hispanic-serving institutions, tribal colleges and universities, and community colleges. For example, using enhanced connectivity, the Montana INBRE network, comprising two PhD-granting institutions, five baccalaureate colleges, six tribal colleges, and two research institutes, has successfully brought together research faculty and undergraduate and graduate students to engage in multi-campus, cross-state collaborative epidemiological studies of infectious diseases and environmental health risks.

Harnessing the full power of advanced computational facilities and computer networks and their promise for research and education across all areas of science requires a workforce with the knowledge and skills needed to develop and exploit cyberinfrastructure. The new Cyberinfrastructure Training, Education, Advancement, and Mentoring (CI-TEAM) program in the Office of Cyberinfrastructure at the National Science Foundation (NSF) signals a major federal commitment to join with the nation's science and engineering community in support of this goal. Recognizing the potential for cyberinfrastructure to expand access to state-of-the-art science and engineering research and education, the CI-TEAM program, like NCRR's programs, seeks to broaden participation of groups that are under-represented in science and engineering.

Health information dissemination to community providers & patients

Federal agencies support a wide range of outreach efforts to provide up-to-date health information to the general public and to health care providers and their patients. These include nationwide public campaigns designed to promote good health, requests for public input on sponsored programs, and special programs designed specifically to involve public representatives in the clinical research enterprise. In addition to promoting collaborations between primary care providers and researchers at academic health centers, enhanced connectivity to community health centers via research networks and to consumers via ubiquitous wireless technologies (e.g., cell phones) strengthens lines of communication for health messages and extends the scope and reach of these vital public education and outreach efforts.

The necessarily abbreviated set of research challenges listed above, along with the approaches taken by ongoing projects described in Appendix 2, illustrate the promise of network connectivity, enabling people, computation, shared instrumentation, and data to come together in space and time to address important and difficult problems and to achieve the missions of numerous federal R&D agencies. Successfully addressing these important and difficult problems will allow numerous federal R&D agencies to enhance efficiencies, achieve their missions, and provide better healthcare to the nation. Solving the challenges is beyond the capacity of any one organization's resources, but working together we can leverage existing cyberinfrastructure, produce metrics indicating best practices, and identify priorities for the biomedical research community to insure that agencies with mutual interests can make the most effective investments to maximize return on public investment.

IV. SUMMARY OF PRESENTATIONS AND DISCUSSIONS

PRESENTATIONS

The workshop began with presentations from NIH- and TATRC-supported researchers illustrating the range of projects that can be pursued through the formation of appropriately provisioned networks. The presentations outlined key challenges and lessons learned and focused on best practices.

Lariat Project
Gwen Jacobs, Ph.D., Montana State University

Impact:
- Lariat money catalyzed a big increase in state investments in cyberinfrastructure
- Collaboration with Northern Tier Network Consortium will establish a high-speed fiber optic network linking multiple cities and academic institutions across Montana, providing a four-fold faster connection to MSU than would have been provided by Lariat alone
- Building buzz for e-science at MSU: workshops on grid computing, remote real-time access to high-field protein NMR facilities in Washington and Wisconsin

Major challenges:
- Communication within and between institutions and between scientists and academic CIOs
- Adoption of collaborative mind-set to identify and develop driving biological research problems (application drivers)
- Access to commercial high-speed fiber from campus edge
- Overburdened campus local area networks (LANs) linking campus buildings

Lessons learned:
- Lasting partnerships and effective interpersonal relationships are key to success
- Building the wide-area network (WAN) is the easy part: each local campus network (LAN) presents unique challenges

Biomedical Informatics Research Network (BIRN)
Mark Ellisman, Ph.D., University of California, San Diego

Network bandwidth is doubling every nine months (for well-endowed schools, at least); how does this change the way we do science?
- Breaking down barriers between scientists, disciplines, and institutions
- Integrating new participants into expanding research teams
- Promoting and facilitating sharing of data, expensive tools, and expertise
- Must grapple with trade-off between information security and ease of use

RCMI Translational Research Network (RTRN)
Keith Norris, M.D., Charles R. Drew University of Medicine and Science

Joining together investigators supported by NCRR's Research Centers in Minority Institutions (RCMI) program, the RTRN is designed to facilitate collaborative clinical research focused on health disparities experienced by minority populations. The emerging network comprises a consortium of clinical investigators and basic scientists from several RCMI-funded Clinical Research Centers (CRCs), other NIH-supported CRCs, community health centers and other organizations with an interest in health disparities, and a data and technology coordinating center. The goal is to translate research from the bedside to the community and back in order to achieve improved community health outcomes. The RTRN will facilitate training of clinical investigators; distributed clinical data management, data mining, and data sharing across health disparity areas; and access to information related to health disparities for basic and clinical researchers, academic and practicing physicians, patients, and the lay public. Initial successes will pave the way for a nationwide network linking a wide array of institutions conducting clinical and translational research.

Major challenges encountered so far:

- Data sharing issues, e.g., intellectual property concerns, security (getting behind firewalls at multiple institutions); interoperability of different health information systems at the various participating sites
- Institutional inertia toward adopting a culture conducive to team science

Biomedical Computing Collaboration Challenges
Chris Johnson, Ph.D., University of Utah

The research community desperately needs better software for biomedical computing:

- Flexible, extensible, robust software environments
- Tools for data integration
- Meta-component model to enable pieces to work together

Software engineering is extremely important and costly, yet often overlooked by U.S. science funding agencies. More money is needed especially for production software engineering and maintenance (as opposed to experimental software development).

Efforts to build and integrate research networks like BIRN, Lariat, NCBCs, HealthGrid, etc. must be based on the following principles:

- Driven by user needs
- Accessibility and usability
- Integration and extensibility
- Verification and validation
- Performance and control
- Open source + open data = open science

<u>Center of Excellence for Remote & Medically Underserved Areas</u>
Mike Shanafelt and Rob Dillon, St. Francis University/CERMUSA

Principally funded by TATRC, CERMUSA demonstrates and assesses best practices in providing healthcare services and education utilizing appropriate, available technology to serve the needs of remote and medically under-served areas. CERMUSA's Telehealth prototypes use computer and communications technology to provide medical services via teleconferencing, including clinical specialty consultations and assistance in surgical procedures. Telehealth resources also enable general practitioners and other health care providers to receive education and training on various subjects from specialists anywhere in the world. Partnerships with rural healthcare organizations are developed to explore the feasibility, reliability, and impact of advanced telecommunications, wireless technologies, and medical information systems and then to compare, contrast, and analyze the types of medical information technologies that will meet the needs of the community and its hospital in the delivery of health care services. CERMUSA also has an education mission, helping students learn about the potential value of Internet2 for providing enriching educational content. CERMUSA workshops in rural school districts feature demonstrations of various tools to make effective use of the huge data handling capability of Internet2.

These individual project presentations created context, outlined pivotal concepts, and spurred ideas for the facilitated discussions that followed.

FACILITATED DISCUSSION SESSIONS

Following the presentations, the first facilitated discussion session explored lessons learned from previous and ongoing networking projects and prepared participants to address in a subsequent session key questions and challenges.

Session I: Lessons Learned, Key Questions, and Challenges
Moderators: Steven Corbato, Internet2; Mark Ellisman,University of California, San Diego; and David Lassner, CIO, University of Hawaii.

David Lassner discussed the Campus Expectations Task Force (CETF) (www.internet2.edu/cetf). CETF was formed in February 2005 to reexamine expectations for the Internet2 community in light of accomplishments since Internet2's inception in 1996. Based on CETF lessons learned, Lassner solicited participant feedback on what is needed to succeed in this endeavor. CETF lessons learned:

- Partner institutions must be committed to innovation in order for innovation to be functional and sustained.
- Commitment to shared infrastructure (advanced networking, security, help desks, etc.) within the community is vital—and these services must be delivered in secure and flexible ways.

Participant responses and comments:

- Support the people that do the research, not only through technological assistance but through recognition of researchers to promote and foster “virtual collaborations” within departments and institutions, and between institutions.
- Promote and maintain network access, flexibility, safety, and support. Take advantage of any and all bandwidth expansions as they become available.

Mark Ellisman discussed lessons learned and challenges for the BIRN project:

- Change, while necessary, can be a destabilizing agent to work in progress. There are times when innovation must be held back in the service of short-term project goals.
- Expert advisors are underutilized—they should be “in the loop” and fully utilized. Don't feel like you have to reinvent the wheel every time.
- Avoid the "field of dreams” model. Instead, seek well-articulated projects with realistic and achievable goals, and give them stable, full-time management.
- Conflicts among researchers must be mediated and managed. Turf battles, confusions, and insecurities about intellectual property ownership, etc., must be addressed and managed in order to keep projects on track, productive, and cost-effective.

Participant responses and comments:

- Project management is inadequately addressed. Poor management is often a liability in networking and connectivity.
- Software development is indeed falling through the cracks, echoing a theme from Chris Johnson's presentation. *Formation of research networks linking shared user communities can stimulate software development and should therefore be encouraged.*
- Cross-disciplinary collaboration is critical. Gaps must be bridged between computer and biomedical scientists in order to optimize research opportunities and project potentials. Some scientists refuse to share any data under any circumstances, thereby impeding research imperatives as well as training of future generations of scientists. Funders need to enforce existing data sharing policies.
- Many hospitals have firewalls compliant with Health Insurance Portability and Accountability Act that simultaneously limit scientific computing and connectivity. Moreover, most hospitals work with pre-determined bandwidths of an arbitrary “standard clinical environment.” Suggestion: Build your own networks to meet your own specific needs. Data standardization is driven by user communities who want to share.
- Bandwidth requirement metrics should be developed for different types of applications (e.g., e-mail vs. multicast videoconferencing) to inform needs assessments and develop appropriate application-driven solutions.
- Connectivity needs at ambulatory care practices, e.g., community clinics and health centers, must be considered and dealt with in order to foster and expand adequately powered community-based clinical and translational research, because that's where the patients are.

During a working dinner session, participants divided into breakout groups to focus on the "Key Questions and Challenges" posed in the pre-meeting white paper (see below), and to record group responses, comments, and recommendations for near-term (3–5 years) priorities for supporting connectivity for biomedical research (Section IV below).

Session II: Priorities, Strategic Partnerships, Next Steps
Moderator: Steven Corbato, Internet2

KEY QUESTIONS AND CHALLENGES

1. Is existing network infrastructure adequate to support interdisciplinary research across the health science spectrum? Will refinement or expansion of current network models suffice to meet anticipated needs, or are new models needed?

Our nation's research and education communities have come to recognize and embrace the power of high-speed networks for meeting their objectives. Through often uncoordinated investments from the public and private sectors, the underlying cyberinfrastructure is evolving rapidly, with connections extending to more and more sites. However, many academic institutions still lack high-speed connections. As various government agencies consider how to address this problem, they must carefully weigh evolving network models. For instance, regional optical networks (RONs) represent facility-based networking built with owned assets, in contrast to the Internet2 Abilene model of an IP-based research and education network using shared commercial assets. A key consideration is the extent to which federal science agencies should invest further in national high-speed backbones like Abilene Network and National Lambda Rail (NLR). Ultimately these may become unnecessary for most purposes, but that is not the case today. Conversely, large national backbones, both NLR and Abilene, cannot meet current needs without the help of RONs. So, in addition to connecting academic institutions to emerging RONs, it is critical to define gaps and intersections between those RONs and the national research network backbones.

"Condominium fiber networks" use customer-owned fiber links to commercial ISPs, often with unlimited bandwidth. This approach is increasingly popular among schools, universities, and businesses, but growing struggles over net neutrality, tiered pricing, and federal regulation suggest that current commercial high-speed internet market structures may impede future growth of academic networks. Alternative models include transit exchanges (TXs) using municipal networks, which are relatively cheap compared to commercial ISPs. Like shopping malls, TXs need "anchor tenants," e.g., universities, big healthcare systems, and public agencies. By building out "first-mile" links to increasingly ubiquitous fiber, universities and medical centers can bring their campuses to a RON via a TX. Key issues include incentives for ISPs to provide services at the TX and ways to integrate TXs into regional networks. Wireless mesh networks with built-in peer-to-peer (P2P) protocols also merit consideration. Though P2P on a wireless mesh network is a breakthrough idea, enterprises must control information flow by building a

Faraday shield around buildings and/or banning personal computing devices within the enterprise zone. This has significant implications for research and health care IT efforts.

Biomedical research requires dedicated infrastructure that offers high-performance computer network capacity and value-added services such as data security, privacy, database federations, and grid computing. Network nodes include local, regional, national and international endpoints, including federal government research facilities, state public health laboratories, academic institutions, hospitals, community clinics and other healthcare centers. To serve this broad community, new network structures are needed, beyond the familiar IP over commercial assets. These structures must be reliable, innovative and adaptive, fast, cheap, and simple to use. In order to create a sustainable business model, next-generation academic networks will need to provide value for the health care sector as well. One way to do this is to leverage the natural intersections between health research and health care to better coordinate and optimize investments in IT infrastructure. Different kinds of data to be shared over such integrated health networks (e.g., text, lab codes, genetic data, images, video, etc.) will require different network resources. Classifying biomedical data by required transmission rate could form the basis for assessing the adequacy of existing network access, allowing case-by-case analysis of the need for connectivity upgrades.

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2. Is existing network infrastructure adequate to bridge academic health centers and community health care providers in order to foster and stimulate community-based clinical and translational research? If not, what are the gaps, what will it take to close them, and how should efforts to close them be funded and prioritized?

The NIH Roadmap for Medical Research (http://nihroadmap.nih.gov/) envisions a major role for health care providers. Researchers therefore have a vital stake in emerging health care IT systems as emphasis shifts toward multi-site clinical studies and community-based clinical and translational research. Community-based research will require commitment of resources in the community settings where the work is to be conducted. Physicians and patients must work together with academic investigators to avoid needless duplication of efforts and build versatile and secure information networks that enable innovative research on real-world problems such as co-morbidities/multiple morbidities and gene-environment interactions. For example, state-of-the-art optical networks, such as those being developed by the National Lambda Rail to provide interactively controlled imaging instruments with HDTV feedback for structural biology, also support new telemedicine applications, showing how advanced network architecture can serve multiple critical missions. However, health care providers, particularly those affiliated with relatively small practices, need real and sustainable incentives to seek and utilize access to advanced networks, as well as training and resources for ongoing technical assistance.

Building bridges must be guided by understanding the value added for all stakeholders. TATRC's HealthGrid concept offers one promising approach in which medical data can be stored, processed, and made easily available to researchers, physicians, healthcare organizations, the public health sector, health care administrators, and individual citizens. Paralleling the U.S. military's move towards "Net Centric Warfare", a "Net Centric Healthcare" environment can enable and enhance research, development, education and patient care within the Army and the Military Healthcare System (MHS) in general. With necessary security guarantees, respect for ethics and observance of standard regulatory frameworks, such an infrastructure allows association of post-genomic information and medical data, opening up new ways to improve health care across a continuum of sectors. With appropriate patient protections, this model could be adapted to the civilian health arena. Potential benefits to society include improved population health; an end to health disparities; reduced health insurance costs for employers; reduced Medicare claims; and reduced Medicaid costs for states.

In the first decades of broadband technology and Grid computing, many of these benefits have not been realized. While challenges exist, most notably privacy and information security concerns, they are not insurmountable; through concerted effort by all stakeholders in collaboration, a research roadmap and funding plan must be developed to address them over the next three to five years. A consensus that the use of Grid technologies for biomedicine is at a developmental "choke point" beyond which a dramatic expansion of its utility and functionality can be realized makes it imperative to identify these challenges and craft a plan to surmount them in order to transform the practice of medicine and health care delivery as we know it.

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3. What are the needs of minority-serving institutions and institutions in rural or remote areas, and how can these needs be addressed to enhance opportunities for broader inclusion in biomedical research?

Building on experiences from recent networking projects, successful approaches for identifying resources and optimal technologies can be realized. Lessons from the Lariat Project can guide next steps in extending advanced cyberinfrastructure to developing research, education, and healthcare institutions nationwide, including rural hospitals and clinics, minority-serving institutions, and tribal health organizations. This ambitious undertaking will require close collaboration among federal science agencies, in partnership with academic and private sector organizations, to identify available resources and optimal technologies and approaches that recognize the varying needs and the diversity of driving research challenges at those institutions.

Potential partners include the National Center for Minority Health and Health Disparities at NIH and AHRQ and HRSA, which support research programs in community health centers. HRSA's Health Disparities Collaboratives (HDC) program supports research at some of the same community health centers involved in RCMI-supported Comprehensive Centers on Health Disparities. Lack of support for IT resources at many community centers is a major barrier to participation in research partnerships with academic health centers. HRSA HDCs have successfully implemented IT tools to improve learning and the spread of health care practice change. For example, their health disparities web portal gets 800,000 hits per month. A relationship between HRSA and NCRR programs could strengthen linkages between communities and relevant research, and bring cost savings due to adoption or adaptation of HRSA's IT tools by NCRR grantees to share information, encourage interaction, and disseminate research findings.

The use of expanded connectivity as a tool for education and information dissemination is critical. However, the education and training of individuals capable of maintaining and effectively using the enhanced cyberinfrastructure will be a substantial challenge, especially for underserved areas. Another major challenge is how institutions will pay for it, particularly smaller rural institutions with limited infrastructure. Solutions will most likely involve ongoing costs. Equitable distribution of support is critical to avoid placing many smaller institutions in underserved areas at a major disadvantage. Negotiation of consortia arrangements with providers might be a useful route to explore in such areas. Whether for local area networks, campus backbones, or wide area networks linking investigators to colleagues around the globe, support for enhanced connectivity should be targeted to developing institutions in proportion to the scope of collaborative research and training activities, including collaborations with the broader science and education community.

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4. Will the private marketplace and/or state and local governments be willing and able to shoulder the costs of developing and sustaining network infrastructure that meets anticipated research needs and ensures broad access to national and international research assets?

Public-private partnerships are central to the development of cyberinfrastructure for biomedical research. Corporate partners have been critical for the development and operation of the Abilene Network, for moving forward advanced applications supporting research and education, and for ongoing technology transfer. Partners such as Qwest, Nortel, Cisco and Juniper Networks provided critical corporate contributions of service, product, and mindshare that helped to launch Internet2. Each commercial organization has a unique value proposition that motivates its involvement, yet all are focused on realizing the potential that advanced networking, middleware, and applications hold for research and education, and the opportunity to shape the future of the global Internet.

Supporting cyberinfrastructure for biomedical research also serves the interests of Web content providers and organizations that serve technology consumers. Commercial organizations with an interest in the biomedical community and a connection to high-performance networks can benefit by being plugged into a unique worldwide technology testbed where they can work together, develop prototypes, and move the resulting technologies into production and regular use. For example, Internet2's corporate members are incorporating advanced technologies into product prototypes, using new interactive collaboration applications to connect scientists at globally distributed laboratories, and developing new forms of advanced media. This type of relationship benefits both early-stage and established companies from diverse sectors.

Although the private marketplace clearly has an interest in research networks, the commercial service providers cannot in all cases be relied upon to develop and sustain broadband access over the long term, especially in rural and impoverished urban areas. Continued public support will be essential, just as with roads and libraries. Indeed the government acknowledges this with its ongoing Internet service subsidy through the Universal Service Fund administered by the Federal Communications Commission. The federal government, in partnership with state and local governments and the private sector, must maintain an active role in coordinated efforts to facilitate provision of local and regional network services, e.g., subsidize RON build-outs, to insure that national research and health care IT assets are readily accessible to all.

Of particular importance for medical research, public institutions and the private sector must work together to provision the network infrastructure needed for community-based clinical, translational, and health services research in partnership with health care providers, especially in underserved urban and rural regions. If the government is to continue play a key role in sustaining computer networks for such purposes, federal science agencies should provide direct grant support for connectivity infrastructure, akin to other shared research resources like computers and advanced instrumentation, rather than treating connectivity like a basic utility akin to telephone service.

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5. If further development and expansion of research networks requires federal support, how can funding agencies balance the needs of their own missions against opportunities for collaboration where mutual interests exist? If collaborative approaches are warranted, how will agencies ensure adequate planning, coordination, and evaluation of inter-agency programs?

A key step toward future collaborations will be to inventory publicly and privately supported cyberinfrastructure programs that impact health research and health care, including regional and national networking activities. Key questions include: Who is doing what where? How do existing and planned future network infrastructures support the desired research, education, public health, and clinical activities? Do we have a good enough vision of what that infrastructure environment looks like now so we can focus on the resources necessary to improve and sustain it?

Stakeholders could address these questions collaboratively through a national coordinating body comprising academic, industry, community, and government (federal, state, local, and tribal) partners, perhaps along the lines of the American Health Information Community but with a strong research and science education focus. Within the federal government, the National Coordinating Office for the Networking and Information Technology Research and Development (NITRD) Program is well-positioned to promote interagency communication and collaboration on networking efforts, in alliance with NSF's new Office of Cyberinfrastructure, the Office of the National Coordinator for Health IT in the Department of Health and Human Services, and the Interagency Health Information Technology Policy Council.

Whatever shape the evolving network infrastructure takes, criteria must be established for evaluating outcomes measures, process measures, fiscal measures, security, interoperability, and quality of service. Programmatic evaluation should include measures of stable bandwidth available on demand; traffic volume before and after connectivity upgrades; the number and productivity of networked research projects (e.g., patient recruitment, publications); productive virtual meetings (e.g., via Access Grid); remote access to and utilization of advanced instrumentation and other distributed resources; and implementation and utilization of online education and training programs.

Responses and comments:

- *Existing infrastructure is inadequate to support interdisciplinary research across the scientific spectrum.* Recommendation: Consider what level of expansion to existing networks will be needed to accommodate coming research priorities. Key question: Since existing and anticipated bandwidth needs, along with past and current successes, drive demand, how do we scale our needs?
- *Existing infrastructure is inadequate to bridge academic health centers and community healthcare providers.* The NIH Roadmap for Medical Research (http://nihroadmap.nih.gov/) envisions a major role for health care providers. Researchers therefore have a vital stake in emerging health care IT systems as emphasis shifts toward multi-site clinical studies and community-based clinical and translational research. Community-based research will require ongoing commitment of resources in the community settings where the work is to be conducted. Significant improvements are needed in connection to end-users, e.g., community health providers, developing institutions, and especially minority academic health centers, as many face bandwidth limitations—sometimes very significant limitations.
- *Expanded government support is needed to foster the development of community-based clinical and translational research partnerships*. However, long-term payoffs to society resulting from better engagement of communities in health research will include improved population health, fewer health disparities, reduced health insurance costs for employers, reduced Medicare claims, and reduced Medicaid costs for states.
- *Big opportunities exist for monitoring population exposures and reactions to environmental factors; these should not be limited to big cities and academic health centers.* Appropriate collection and analysis of population health data will be vital for understanding and reducing health disparities experienced by minority groups and under-served urban and rural populations.
- In order to close gaps between academic health centers and community-based healthcare providers, *create and promote environments in which there is trusted sharing of (often remote) resources*. [*Steve Corbato* translated this concept as “beyond collaboration lies federation.”]
- *Look at community needs first, e.g., local hospitals and clinics*. Ultimately, bandwidth increase will reach individual providers—as improved connectivity permits their increased involvement in research—but for now, look to bandwidth

enhancement at the community level. View network infrastructure and connectivity in terms of distinct community characteristics and needs.

- *Focus on human infrastructures ("human capital") as much as on applications, hardware, and networks*. "People don't know what they don't know," noted one discussant, pointing to the need for network participants (or potential participants) to be educated as to what is possible both for themselves and for their communities.
- Enhanced cyberinfrastructure will help level the playing field for minority-serving institutions—but it is not enough. *Funding and training remain vital*.
- *Prioritization is key for minority-serving institutions, since adequate funding resources will not be optimum in the near future*. "Minority institutions must carefully and wisely prioritize by way of maximizing opportunities for enhanced connectivity."
- Some minority-serving institutions are neither rural nor remote. "We have resources," noted one participant, "but we don't have enough to be competitive." *Truly new thinking is needed to help minority-serving institutions join the mainstream of connectivity and discovery*.

V. PRIORITY RECOMMENDATIONS

- **Strengthen communication and coordination between federal funding agencies, academic groups, and public and private sector entities engaged in cyberinfrastructure and telecommunications network development.**

- **Exploit existing government-wide forums to promote interagency collaboration and innovation the cyberinfrastructure arena.**
    - Networking and Information Technology Research and Development (NITRD) Coordinating Groups
    - American Health Information Community (AHIC)
    - Interagency Health Information Technology Policy Council

- **Increase support for software engineering and maintenance to enable collaborative sharing of data and tools on a production scale.**

- **Increase support for IT personnel recurring costs.**
    - Professional project management: bridging the scientific disciplines
    - Operational project management: performance sites and data

- **Nurture a culture of collaboration within and between academic health centers to foster interdisciplinary team science.**
    - Based on large-scale, complex driving research challenges
    - Emphasizing communication and data sharing across disciplines
    - Encouraging academic rewards, recognition for collaboration

- **Close wide gaps in connectivity for minority-serving institutions, developing academic institutions, and hospitals and community health centers in rural and urban underserved areas.**

- **Enhance connections to communities and health care providers.**
    - For community-based clinical and translational research
    - For health care quality, safety, and effectiveness research
    - For health information dissemination to promote healthy behaviors in communities, to better inform academic research, and to increase situational awareness (e.g., biosurveillance, population health)

- **Develop network performance measurement tools and an inventory of network resources and connections.**
    - Performance standards based on end-user experience
    - First-mile connectivity atlas, state-by-state
    - Decision support tools for getting connected (e.g., LAN/WAN cookbook)
    - Bandwidth and quality-of-service needs for different types of tasks

- **Support planning grants to foster the development of collaborative research partnerships spanning the entire health science spectrum.**

VI. CONCLUSIONS

COMMON LESSONS LEARNED FROM RESEARCH NETWORK PROJECTS

- **Connectivity involves people, projects, and software along with network fiber and associated hardware (hubs, repeaters, routers, etc.).**
- **Connectivity serves multiple purposes, so plan accordingly to foster:**
    - **Research (*especially* interdisciplinary research)**
    - **Education and research training**
    - **Public service, e.g., improvements in health care delivery**

CONSENSUS VIEWS ON KEY QUESTIONS AND CHALLENGES

1. **Is existing network infrastructure adequate to support interdisciplinary research across the health science spectrum? Will refinement or expansion of current network models suffice to meet anticipated needs, or are new models needed?**

    - Better connections are needed – both in terms of bandwidth and quality of service – to serve diverse end users who are situated in widely diverse research environments.
    - Advanced research applications (e.g., data visualization, real-time event monitoring) are expected to continue to drive increased needs for bandwidth and better quality of service.
    - Bandwidth constraints are becoming increasingly critical as the complexity and volume of research data grows, especially for developing institutions.

2. **Is existing network infrastructure adequate to bridge academic health centers and community health care providers in order to foster and stimulate community-based clinical and translational research? If not, what are the gaps, what will it take to close them, and how should efforts to close them be funded and prioritized?**

    - Community-based research will require ongoing commitment of resources in the community settings where the work is to be conducted.
    - Significant improvements are needed in connection to end-users, e.g., many community health providers, developing institutions, and especially minority academic health centers, face sometimes very significant bandwidth limitations.
    - R&D for advanced applications (e.g., medical imaging, remote surgery, emerging point-of-care technologies) requires increased bandwidth and quality of service.
    - Low bandwidth and quality of service hinder patient encounters in community research settings, especially in underserved areas
    - In some locations, primarily rural locations, commercial “broadband” (cable or

DSL) is unavailable at any price due to market constraints.
- Unpredictable latency can be a major impediment for busy physicians wishing to engage in community practice-based research.

3. **What are the needs of minority-serving institutions and institutions in rural or remote areas, and how can these needs be addressed to enhance opportunities for broader inclusion in biomedical research?**

   - Minority-serving institutions (MSIs) and remote/rural institutions often have different issues and needs and should not necessarily be lumped together when considering possible approaches or IT solutions.
   - Even urban MSIs can lack last-mile connectivity to advanced networks like Internet2 or National Lambda Rail.
   - Key common issues for developing institutions are staff and funding constraints for IT infrastructure for research.
   - In order for them to be able to effectively participate, developing institutions *must* be included early in the planning process for initiatives designed to promote collaborative research networks.

4. **Will the private marketplace and/or state and local governments be willing and able to shoulder the costs of developing and sustaining network infrastructure that meets anticipated research needs and ensures broad access to national and international research assets?**

   - Emerging regional optical networks (RONs) could help close the gaps between research institutions and high-speed Internet backbones.
   - In concert with networking groups such as Internet2 and the National Lambda Rail and aided by a continuously updated inventory of RONs, federal science agencies could serve as matchmakers to help grantees identify appropriate, affordable connections.

5. **If further development and expansion of research networks requires federal support, how can funding agencies balance the needs of their own missions against opportunities for collaboration where mutual interests exist? If collaborative approaches are warranted, how will agencies ensure adequate planning, coordination, and evaluation of inter-agency programs?**

   - Increase communication between federal programs with mutual interests:
     - NIH, AHRQ, HRSA, IHS for community-based research,
     - NIH, NSF, DoE for high-performance distributed computing.
   - Exploit existing government-wide forums:
     - Networking and Information Technology Research and Development (NITRD) Coordinating Groups,
     - American Health Information Community (AHIC)
     - Interagency Health IT Policy Council

At the core of the NIH Roadmap vision for clinical and translational research is the forging of new partnerships among organized patient communities, community-based health care providers, and academic researchers. In the past, all research for a clinical trial could be conducted in one academic center; that is unlikely to be true in the future. Roadmap initiatives promote the creation of better integrated networks of academic centers that work jointly on clinical trials and that include community-based health care providers who care for sufficiently large groups of well-characterized patients. These large studies are often best conducted through networks of investigators who are equipped with tools to facilitate collaboration and information sharing.

Implementing this vision requires:

- New ways to organize the way clinical research information is recorded
- New standards for clinical research protocols
- Modern information and communication technology that is broadly accessible through widely distributed network infrastructure
- New models of cooperation between NIH and patient advocacy alliances
- New strategies to strengthen the clinical research workforce

Re-engineering the clinical research enterprise will promote and expand clinical research networks that have the capability and flexibility to rapidly and efficiently conduct high-quality clinical studies addressing multiple research questions. Accomplishing this will require appropriately placed and sustained research infrastructure to enable effective collaboration across sites and disciplines.

Toward that end, workshop participants expressed strong and broad support for renewed efforts to strengthen partnerships among funding agencies, academic health centers, non-profit research and education organizations, health care providers, and the commercial information and communication technology sector to better coordinate, expand, and optimize investments in network infrastructure.

In particular, participants highlighted the need to leverage the natural intersections between biomedical research and health care, e.g., clinical research informatics and electronic health records, respectively, in order to foster the development of clinical and translational research networks that broaden community participation and accelerate the pace of discovery, leading to better health outcomes for all.

VII. CONTACT INFORMATION

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For more information about NCRR, please visit www.ncrr.nih.gov.

APPENDIX 1
WORKSHOP AGENDA

Supporting Connectivity for Biomedical Research: Executive Session
April 24, 2006
Agenda

3:30-4:00 p.m.	**Registration and refreshments (outside Salon B)**
4:00-4:05 p.m.	**Welcome and charge to the group** *Steven Corbato, Internet2* *Michael Sayre, Ph.D., NCRR Division of Research Infrastructure* *Mary Kratz, MT, TATRC and University of Michigan*
4:05-4:20 p.m.	Lariat Project *Gwen Jacobs, Ph.D., Montana State University*
4:20-4:35 p.m.	**Biomedical Informatics Research Network (BIRN)** *Mark Ellisman, Ph.D., University of California, San Diego*
4:35-4:50 p.m.	Translational Research Network *Keith Norris, M.D., Charles R. Drew University*
4:50-5:05 p.m.	Center of Excellence for Remote and Medically Underserved Areas *Mike Shanafelt, St. Francis University/CERMUSA*
5:05-5:20 p.m.	Biomedical Computing Collaboration Challenges *Chris Johnson, Ph.D., University of Utah*
5:20-6:30 p.m.	Facilitated discussion: lessons learned, key questions and challenges *Moderator: Steve Corbato* *Co-facilitators: Mark Ellisman, UCSD* *David Lassner, CIO, University of Hawaii*
6:30-7:30 p.m.	**Buffet dinner and continued discussion (Salon C)**
7:30-9:00 p.m.	**Facilitated discussion: priorities, strategic partnerships, next steps** *Moderator: Steve Corbato*

APPENDIX 2
EMERGING NETWORKS AND TEST-BED PROJECTS

Regional Research and Education Networks and Public-Private Partnerships

The Lonestar Education And Research Network (LEARN) is a cooperative effort to provide high-speed connectivity between 33 institutions of higher education in Texas and links to research networks across the country in support of research, teaching, health care, and public service. LEARN aims to enhance Texas' research and economic competitiveness and provide state-of-the-art, cost-effective data communications that enable effective education of students around the state. Similar efforts in other regions include public-private partnerships. The Southeastern Universities Research Association (SURA) and AT&T inked an agreement in 2003 providing SURA with no-cost access to 6,000 pair miles of dark fiber on AT&T's network and an additional 2,000 pair miles for network research. In part, SURA's goals are to increase collaboration of regional bioinformatics resources with a view toward establishing a regional BioGrid.

IDeA Networks of Biomedical Research Excellence (INBRE)
http://www.ncrr.nih.gov/resinfra/inbre.asp

NCRR's INBRE initiative supports statewide networks for biomedical research, education, and training in 22 states and Puerto Rico. Much like SURA's aim to build regional bioinformatics resources, each INBRE supports a bioinformatics core facility to provide access to distributed databases, informatics tools, and training for undergraduate and graduate students engaged in research in a wide variety of urban, rural, and minority-serving institutions. INBRE medical schools are well positioned to address national needs in developing a diverse, inclusive research workforce that is well versed in biomedical informatics for health research and health care.

Lariat Project http://lariat-west.org/

NCRR's Lariat Project is a regional networking effort bringing high-speed connectivity to biomedical researchers in a consortium of academic institutions in Montana, Idaho, Nevada, Wyoming, Alaska, and Hawaii. The project has installed dedicated research network links from each site to the Abilene backbone and the National Lambda Rail via regional points-of-presence in Seattle, Denver, and Sunnyvale, and to major bioinformatics resources at the University of Washington. Lariat cyberinfrastructure eliminates crippling choke points, ensures scalable growth, and enables provision of dedicated bandwidth for specific research applications and science education. Enhanced connectivity allows scientists and educators to take advantage of the wealth of research resources and expertise available across the U.S. and around the world.

Biomedical Informatics Research Network (BIRN) http://www.nbirn.net/

NCRR's BIRN project utilizes emerging advanced cyberinfrastructure to enhance collaborative efforts, integrating data, expertise, and unique technologies from multiple research centers to spur important scientific advances that would be difficult or impossible in the context of individual laboratories. Launched in 2001 with a coordinating center and two test beds and a third test bed added in 2002, the BIRN now involves a growing consortium of more than 20 universities and 30 research groups across the country, with additional connections being made with the international community of neuroinformatics researchers. BIRN test beds emphasize data sharing, integration, processing, and analysis. Although they focus on neuroimaging of human neuropsychiatric disease and associated animal models, the underlying infrastructure for collaboration will be of great value in all areas of biomedical and clinical research. Because very large imaging data sets, in terms of file size and number of files, are being collected at many sites and stored in a distributed fashion, the BIRN stresses the high-speed network to which all sites are connected. It provides fertile ground for testing how to balance moving cycles to the data versus moving data to the cycles, and how to aggregate the results of large automated workflows into meaningful but compact human-readable forms. The BIRN is also addressing some very large computational problems that require grid computing approaches.

Models of Infectious Disease Agent Study (MIDAS)
https://www.epimodels.org/midas/about.do

MIDAS is a collaboration between research and informatics groups to develop computational models of interactions between infectious agents and their hosts, disease spread, prediction systems, and response strategies. The models will be useful to policymakers, public health workers, and other researchers who want to better understand and respond to emerging infectious diseases. If a disease outbreak occurs, the MIDAS network may be called upon to quickly develop specific models to aid public officials in their real-time decision-making processes.

National Centers for Biomedical Computing (NCBC)
http://www.bisti.nih.gov/ncbc/index.cfm?

Progress in biomedical computing requires cross-disciplinary expertise. Supported by NIH, the NCBCs and the teams they bring together produce investigators with broad knowledge that can be applied to biomedical issues, knowledge that incorporates the strengths of biology, computer science, and mathematics. In the short term, biomedicine will benefit from the team approach. In the long term, the NCBCs will build a cadre of researchers who can apply much of the expertise necessary to deploy and support biomedical computing and advance the emerging discipline of systems biology. The trans-NIH Biomedical Information Science and Technology Initiative (BISTI), and its NCBC program, is a bootstrapping approach to that next level of interdisciplinary biomedical science.

Cancer Bioinformatics Grid (caBIG) https://cabig.nci.nih.gov/)

The cancer Biomedical Informatics Grid (caBIG™) is a voluntary network or grid connecting individuals and institutions to enable sharing of data and tools, creating a

World Wide Web of cancer research to speed delivery of innovative approaches for preventing and treating cancer. Over 800 people from more than 80 organizations are working collaboratively on 70+ projects. caBIG is already delivering tools and applications, all freely available to the community and other interested stakeholders. Program milestones, an inventory of tools developed or being developed, guidelines, and papers produced by the caBIG community are available on a public Web site.

National Ecological Observatory Network (NEON) http://www.neoninc.org/

Supported by NSF, the NEON is the first national ecological measurement and observation system designed both to tackle regional- to continental-scale scientific questions with the interdisciplinary participation needed to achieve credible ecological forecasting and prediction. The NEON is envisioned as a continental-scale research instrument consisting of geographically distributed infrastructure comprising cutting-edge lab and field instrumentation, site-based experimental infrastructure, natural history archive facilities and/or computational, analytical and modeling capabilities, all networked via state-of-the-art communications. Scientists and engineers will use NEON to conduct real-time ecological studies spanning all levels of biological organization and temporal and geographical scales. Data will be made publicly available on the Web.

AHRQ National Resource Center for Health Information Technology
http://healthit.ahrq.gov/portal/server.pt?

The National Center for Health IT is a Web-based learning resource center for health care providers seeking help in adopting health IT, including a library with links to more than 5,000 resources identified by AHRQ experts and partner contributors, such as professional societies and nonprofit organizations. Health care providers can receive an IT evaluation toolkit, a summary of key topics such as clinical decision support and health information exchanges, and other resources including current health IT activities and funding opportunities. The center aims to help health care providers at the ground level learn from each other's real-world experience and have easy access to the best information available, bringing lessons of experience together in one place so that providers can avoid problems and achieve greater benefits when they adopt health IT.

Electronic Primary Care Research Network (ePCRN) http://www.epcrn.org/index.php

Funded by the NIH Roadmap Initiative and administered by the Federation of Practice Based Research Networks, the ePCRN allows primary care practices to link with researchers conducting clinical research anywhere in the United States. Its principal aim is to enable the development of an electronic infrastructure that facilitates recruitment of subjects and performance of randomized controlled trials in primary care practices throughout the U.S. This infrastructure, which includes distributed database technology interfaced with a web portal solution and Internet2 components for enhanced functionality and communication, is designed to promote rapid integration of new research findings into primary care practice.

Center of Excellence for Remote and Medically Under-Served Areas (CERMUSA)
http://www.cermusa.org/

Principally funded by TATRC, CERMUSA demonstrates and assesses best practices in providing healthcare services and education utilizing appropriate, available technology to serve the needs of remote and medically under-served areas. CERMUSA's Telehealth prototypes use computer and communications technology to provide medical services via teleconferencing, including clinical specialty consultations and assistance in surgical procedures. Telehealth resources also enable general practitioners and other health care providers to receive education and training on various subjects from specialists anywhere in the world. Partnerships with rural healthcare organizations are developed to explore the feasibility, reliability, and impact of advanced telecommunications, wireless technologies, and medical information systems and then to compare, contrast, and analyze the types of medical information technologies that will meet the needs of the community and its hospital in the delivery of health care services. CERMUSA also has an education mission, helping students learn about the potential value of Internet2 for providing enriching educational content. CERMUSA workshops in rural school districts feature demonstrations of various tools to make effective use of the huge data handling capability of Internet2.

APPENDIX 3
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