Report of the HICSS-42 Symposium on Cyberinfrastructure for Public Health and Health Services: Research and Funding Directions

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ABSTRACT

The Hawai‘i International Conference on System Sciences (HICSS), in collaboration with the National Institutes of Health (NIH) and the Kay Center for E-Health Research at Claremont Graduate University, sponsored a symposium on “Cyberinfrastructure for Public Health and Health Services: Research and Funding Directions.” Held January 5, 2009, the symposium convened researchers, practitioners, federal funders, and journal editors to discuss how to improve cyberinfrastructure (CI) systems and research in public health and health services sectors.

The symposium highlighted the need for cyberinfrastructure (CI) to produce ubiquitous, robust, and effective systems for public health/population health. Daniel E. Atkins III, PhD, professor in the School of Information at the University of Michigan, Ann Arbor, and previous chair of the National Science Foundation (NSF) Blue-Ribbon Advisory Panel on Cyberinfrastructure, provided an overview, with directions for facilitating and improving the use of CI in public health and health services sectors. Dr. Atkins described the technical and social dimensions of CI, and advocated an action-based, use-inspired research direction to guide research, practice, funding, and publishing efforts. In the ensuing panel discussions, participants noted that CI could help bridge the gap between public health and health services, building partnerships between disciplines and sectors, exploring the links between technical and social dynamics in informatics and particular to health, and developing best practices for future research.

The symposium goals were to: 1) determine the dynamics necessary for executing and utilizing CI in public health and health services; 2) examine the requirements of transdisciplinary collaboration; and 3) identify future research directions. Participants thought applying use-inspired research would best utilize CI in the health sector, and determined that CI research should facilitate partnerships and transdisciplinary collaboration among stakeholder groups. Participants advanced research that focuses on patients and access to care, health information exchange, communication, and surveillance, and that improves existing systems by process changes and enhanced interoperability through a system of partnerships.

INTRODUCTION

Cyberinfrastructure (CI) comprises both the technical and social backbone of modern science, research, and related practice. As defined by the "Report of the National Science Foundation Blue-Ribbon Advisory Panel on Cyberinfrastructure,"[1] cyberinfrastructure includes computational advancements and broadband networking, massive storage and managed information, observation and measurement tools, and leadership on shared standards, middleware, and common applications for scientific computation. It also focuses on sharing, efficiency, and increasing the available capabilities across the science and engineering research communities, as well as facilitating new applications, collaboration, and interoperability across institutions and disciplines.

In public health and health services, CI holds the potential for developing systems that will enable new connections between public and population health and health services. CI can manage all facets of the rapidly increasing health data, including their production, access, analysis, integration, storage, and retrieval. CI will also contribute to future advances in sensor networks, high-throughput technologies and instrumentation, automated data acquisition, computational modeling and simulation, and other technologies able to advance public health and health services practices. In addition, CI can influence health behavior and the way health information is provided, accessed, and interpreted by consumers and professionals. Given the dynamics of healthcare reform and the potential role of health information technology in contributing to this change, the future of CI in public health and health services looks promising.

Thomas A. Horan, PhD, associate professor and Director of the Kay Center for E-Health Research at Claremont Graduate University, introduced the symposium objectives:

- To identify key dynamics to execute and utilize CI nationally in public health and health services;
- To examine dynamics of transdisciplinary collaboration across stakeholders and disciplines; and
- To develop future directions for CI research.

(Please see Appendix A for a full symposium agenda and list of presenters).

Identify Key Dynamics of CI for Public Health and Health Services. With the current status of national healthcare reform, information technology and health services are at a tipping point. Beneficial impacts of CI range from scope (individual and population level), to access (who works with CI and/or receives its benefits), to collaboration (reducing research silos, working across disciplines, and disseminating findings). Symposium discussions focused on bridging the gap between CI and public health and health services, obtaining public health understanding and benefits from electronic and personal health records (EHRs and PHRs), and realizing the opportunities in public health surveillance and health communication.

Examine Dynamics of Transdisciplinary Collaboration. A transdisciplinary approach should be fostered among public health and health services stakeholders and disciplines. [2] Inclusive stakeholder groups can form connections between public health and health services by using CI in accessing individual and population level data for public use, developing innovative lines of research, improving practice, acquiring funding, and disseminating findings. CI naturally facilitates linkages across this gap, but interagency, regional, and public-private partnerships need to promote such CI connections.

To realize the full potential of Health Information Technology (Health IT) for transforming public health and health services, the vertical structures now holding scientific and medical information could be reengineered to permit sharing, analysis, and application within and across disciplines. CI can establish interfaces that link existing islands of surveillance data, research, and clinical, and even personal health data maintained by consumers. Collaborative access, analysis, and communication require that technology be designed and implemented in a manner that ensures the highest level of interoperability while also creating incentives for communication.

Develop Future Directions for CI Research. Future efforts should reflect the collaborative and transdisciplinary nature of CI research, as well as the directions and support provided by stakeholders and funders. Such directions/initiatives could promote increased data sharing, computational methods, and interoperability across existing and future systems, as well as partnerships across diverse public health and health services entities. Using existing data models, researchers, practitioners, and funders can focus on integration, interoperability, and development of innovative funding opportunities in the context of EHRs and PHRs.

While these were the key themes for the day, each session provided a distinctive contribution to the elaboration of those themes, commencing with the keynote talk and concluding with a discussion of future directions.

SYMPOSIUM HIGHLIGHTS

Atkins Keynote: Focusing on Pasteur's Quadrant Research Style

Dr. Daniel Atkins, from the School of Information, University of Michigan, began by positing the need to accelerate the research cycle and increase collaboration among and between researchers and practitioners. To facilitate effective research, stakeholders need to determine how they can best collaborate to advance the development and deployment of CI in public health programs and health services. Funding investments should foster the goals of promoting partnerships and integration with other CI-related investments from the national and international sectors.

To facilitate cooperative/collaborative research, Dr. Atkins suggested that researchers, practitioners, funders, and disseminators commit to a "Pasteur's Quadrant" style of research, a marriage between theory and practical applications. In this research style, theory is grounded, inspired, and informed by practical problems and challenges (see Figure 2).

Dr. Atkins impressed upon participants the social and technical connections that inform CI, describing CI as "encompassing organizations, people, policy, and economic sustainability to provide a ubiquitous, robust, and hopefully continuously improving service." Atkins further portrayed CI systems as "transformative tools and systems for individual through population level health services." CI provides a framework for the collaborative growth of knowledge built on the complex and expansive systems that society has nurtured and created. Yet CI also requires support as a platform for knowledge communities, for research, innovation development, and education.

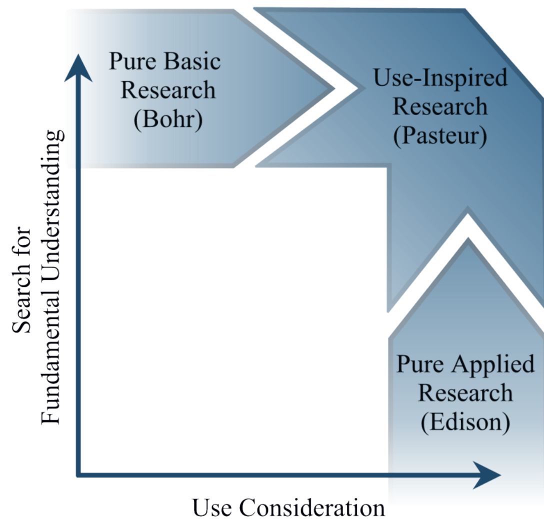

Figure 2. Pasteur's Quadrant, showing how the basic confluence of scientific inquiry with applied research results in innovations and a practical understanding that addresses societal needs. [3]

CI supplies an avenue for transforming the activities of disparate groups involved in conversations about major public health challenges such as health reform, health disparities, and cancer prevention and control. The challenge, according to Atkins, is to optimize organizations to carry out these activities more effectively, on a larger scale, and with broader participation and transdisciplinarity. A functionally complete "collaboratory" that removes silo infrastructure, will help shape the system into a comprehensive CI. In asking how CI can best be utilized for public health and health services, Atkins advocated collaborative research teams cognizant of the social and technical nexus that informs CI, who will work together to initiate use-inspired systems research focused on specific health topics.

Panel: Key Research Challenges and Opportunities

The Research Panel, building on Dr. Atkins' global observations, noted that achieving transformative results in health research requires: 1) adopting a broader, multi-level public health approach, 2) creating collaborative and transdisciplinary approaches, including connections between clinical and public health approaches, 3) conducting action research within Pasteur's Quadrant, and 4) focusing on patient and consumer needs.

Adoption of a Multi-Level Public Health Approach

Healthcare is often narrowly defined and fails to capitalize on emerging knowledge and new clinical indicators. For example, observations by individuals in their homes have great potential to inform existing knowledge. Patti Brennan, PhD, professor of industrial and systems engineering and nursing at the University of Wisconsin-Madison, noted that in order to promote CI within health, transdisciplinary teams must understand unique health-related requirements that are not yet understood by CI-builders – particularly the perspectives of end users such as public health practitioners, patients, families, and caregivers. Health behavior workflow models have the potential to improve healthcare outcomes and enhance collaboration among stakeholders. Workflow studies of actual care delivery can pave the way to designing technologies that will improve health outcomes. Dr. Brennan noted that design innovations might include interactive devices that facilitate knowledge transfer and integration among clinicians and patients.

CI provides opportunities to mitigate information overload by enabling the systematic marriage of human and technological capabilities. CI can facilitate collaborative filtering of data and create economies of information to streamline and accelerate research. Importantly, technicians and social and health scientists have equally important roles in this endeavor, with technology positioned as an enabler, rather than a tool, so that diverse and distributed knowledge communities can work together in transdisciplinary teams.

The Need for Collaborative and Transdisciplinary Approaches

Building on his keynote remarks, Dr. Atkins explained that current research should be driven by a collaborative approach to promote transdisciplinary integrative sciences. The research field requires high performance collaboration environments, not just computation environments. Increasing the intellectual cross-section of distributed knowledge communities will increase the likelihood of transformative results by leveraging existing knowledge through data sharing, and through creating incentives that encourage organizations to share data with the broader community. Dr. Brennan added that practitioner institutions are reluctant to promote data sharing; thus, new incentive structures and a reorientation of the value proposition of data sharing must be developed.

Noshir Contractor, PhD, Departments of Industrial Engineering & Management Sciences, Communication Studies, and Management & Organizations, at Northwestern University, observed that researchers should think of CI as multidimensional networks where people, data sets, data visualization, and conceptual models work together through an informatics system. Researchers are developing ways to diminish the challenges of navigating these networks, finding the best analytical tools and most relevant concepts, and assembling a team of resources, people, and data to meet the challenge. Utilizing these multidimensional networks offers great opportunities to advance research. Given the robust and distributed nature of health research, such CI systems could assist in addressing major health issues including behavioral, chronic, and acute disease domains.

Connecting Clinical and Public Health Approaches

The deployment of CI has the potential to enable new scientific applications in both clinical practice and public health. Two areas, health communication and public health surveillance, are particularly well positioned for future research.

Clinical practice typically involves face-to-face encounters in the practitioner's office; however, this may not be the most efficient or useful approach. M. Christopher Gibbons, MD, MPH, associate director of the Johns Hopkins Urban Health Institute and assistant professor in the Hopkins Schools of Medicine and Public Health, noted that researchers should explore other opportunities for interaction, from interactive television to health-on-demand, which facilitates delivery of clinical interventions in a variety of forms and settings across a CI. Technologies that enable decision-supported diagnosis or diagnosis in the absence of face-to-face human input are also worth exploring. CI offers opportunities to expand and transform telemedicine by reaching widely dispersed communities and hard-to-reach populations, which can reduce health disparities and improve health behavior.

The panel discussed numerous research opportunities for public health practice, ranging from data mining to knowledge management, and how research endeavors can influence population-level public health. Dr. Contractor noted, "A lot of work exists in tobacco research, but it is all in pockets. Some people know about it, some do not. Because people will not talk to each other, this knowledge is separate … data are not connecting well together." As this example suggests, CI could enable

researchers to mine legacy data sets and analyze adverse events to glean new information that would improve prevention at the individual and population levels. Through environmental surveillance and linkage of economic, social, and health-related data, communities can improve their public health planning and potentially enhance population health outcomes.

Action Research in Pasteur's Quadrant

Dr. Brennan highlighted the importance of the social and use-inspired aspects of CI systems by noting that PHRs "have broken the mold in the application of technology for the collection and utilization of health information." Moreover, "when PHRs are thought of as a suite of tools, they achieve their maximum impact by using new kinds of clinical and behavioral science to motivate and condition behaviors that can potentially lead to better health outcomes." Rapid prototyping and design innovation are critically important and can lead to integration of consumer, clinician, and technological possibilities, accelerating the impact of CI on public health and health services.

One challenge for researchers is to understand why and how Health IT is changing, and how technology can help the public health and health services domains. CI provides access to information by improving patient-provider communication, patient education, and the ability to reach diverse populations. These Health IT capabilities can enhance community health by developing targeted community health profiles, improved public health planning, and enhanced local public health communication and partnerships.

New research should break away from classical models, described by Dr. Brennan as "insufficient to guide discovery and evidence of CI." She added, "A Bayesian approach is needed, as are workflow studies to address the current practice of healthcare. This kind of research innovation is critical in order for CI to achieve its intended results." Use-inspired action research should be fostered utilizing analytical models that partner with communities, and investment in basic science discovery should occur in tandem with evaluating new models of public health and health services delivery.

The National Cancer Institute's (NCI) Cancer Research Network (CRN)[1] is an example of such action-oriented research. Cancer, the leading cause of death for people aged 45-64 [4], carries an enormous financial cost and a 2005 study cited by Bradford W. Hesse, PhD, chief of the Health Communication and Informatics Research Branch at NCI, a 1% reduction in cancer incidence would represent over $400 billion in healthcare savings. [5] Through the 14 health maintenance organizations (HMOs) that make up CRN, NCI has addressed a public health issue of daunting proportions by increasing the number of screenings and taking a proactive approach to prevention within real-world clinical settings. Indeed, the CRN could become a remarkable social and technical infrastructure that improves health quality and effectiveness as well as reducing costs.

Addressing/Focusing on Patient and Consumer Needs

Understanding and incorporating patient concerns is necessary when thinking about CI in health. As mentioned earlier, CI should be aligned with clinical and public health workflows spanning the full spectrum of stakeholders: public health professionals, clinicians, patients, *and* consumers. The current fragmented health infrastructure lacks the reliability, ubiquity, and quality required to network all available health-related data. This lack of consistent and secure availability of de-identified patient information is an issue that impedes CI's ability to impact public health by cross-disciplinary collaboration.

[1] http://crn.cancer.gov

Knowledge of human behavior is also essential to improving health outcomes. For public health practice in particular, Dr. Gibbons commented, "Researchers need to gain a greater understanding of the fundamentals of human behavior and how they can improve health outcomes in order to develop a disparity reduction strategy." Scientists already have the beginnings of socio-behavioral genomics, which explores associations between genetics and behavioral characteristics and applies those understandings to the population as a whole. Dr. Gibbons noted that these insights should be expanded to implications for drug development, behavioral sensitizing, and transdisciplinary integrated science – with its potential for redesigning the public health system from its current reactionary form to one that is proactive and preventive. Technologies are not solely a mechanism for delivering interventions, but can be agents of intervention.

Panelists commented that health is a uniquely person-centric attribute, a characteristic that should define the scope of CI within public health and health services. CI offers opportunities to extend patient participation in health services to the underinsured and uninsured, groups that have a disproportionate share of poor health [6]. This challenge reaches across organizations, people, and communication, providing a critical opportunity to advance ways of thinking about technology and to develop an information integration strategy for laypeople. The next challenge is to understand how health information is accessed, interpreted, and managed.

Panel: The Practice of Using Cyberinfrastructure in Health Systems and Public Health

The Practitioner Panel provided examples of existing structures within health services and public health systems, discussing their advantages and disadvantages and how they can be improved and replicated. The panel demonstrated how informatics could improve the integration of EHRs/PHRs, data accuracy, surveillance systems, and clinical trials.

Implications of Kaiser Permanente's Experience with Cyberinfrastructure

Kate Christensen, MD, medical director, Kaiser Permanente Internet Services Group, discussed Kaiser's use of incentives to promote technology implementation, integration, and use, particularly through PHRs. Kaiser's system provides incentives to physicians to promote prevention, which facilitates interaction with patients. Designed from a patient's perspective, the system's goal is to make information more transparent. For example, patients have access to laboratory results and can communicate with physicians via email. The success of the Kaiser initiative provides a model for researchers and practitioners to evaluate and replicate in other settings.

When deployed, maintained, and integrated appropriately, PHRs can streamline health provider encounters with patients while adding health monitoring and education. However, PHRs must reflect awareness of their demographic. Dr. Christensen observed, "The future of PHRs [will] bring a new set of assumptions and challenges in how patients use health data, use electronic health systems, use the health system, and afford any healthcare."

A fully functioning PHR would accommodate three types of data entry: patient entry of current health information, data populated through integration with an EHR, and a combination of these. For example, some diagnostic tests, such as blood pressure measurements, are more current when routinely tested at home. The PHR makes it possible for patients to self-test, record their information in the PHR, which then populates the EHR. System-generated data are not the only legitimate data, and Kaiser finds that the most useful data come from patients and their families.

Achieving the Perfect Storm of Cyberinfrastructure, Practice, and Research

Numerous intersections between clinical research and clinical practice have resulted from the advent of CI in the health services sector, creating "a perfect storm" with respect to the ability to conduct research. These intersections should be used to facilitate increased dialogue and collaboration among practitioners within and between public health and health services. CI can improve existing public health and health services systems, reviewing them for overlapping and opportunities, lessons learned about process improvements, and improved data sharing across disciplines. Through its capacity to initiate ground level overhauls at the process level, CI is more than just IT. CI allows analysis of existing data by practitioners and organizations to determine the size and scope of the problem, and provides opportunities to clean up back end processes, front end interactions with patients, and other informatics opportunities.

Thomas M. Vogt, MD, MPH, program director, Kaiser Permanente Center for Health Research, described the importance of developing best practices and standardized methodologies for data use. To increase efficiency, data options must be narrowed and coding systems streamlined. Greater adherence to emerging coding and entry standards (e.g., HL7) should be encouraged, as well as a standard methodology for data analysis, to ensure consistent information across EHRs. Both EHRs and PHRs can provide care- and outcome-related information that opens opportunities for research breakthroughs. However, if information is based on faulty or incorrect data, researchers and practitioners may not identify the problem or may reach incorrect conclusions.

Regional and Cross-Agency Collaboration in Public Health. CI can improve surveillance through automated links among data in EHRs, clinical lab reports, and public health databases. The challenge is to adhere to privacy and security standards, particularly in using patient data to measure trends. "An important first step will be interfacing and expanding state immunization registries and advancing creative technologies such as 911 databases to alert emergency departments and to improve professional and public education," commented Linda Hill, MD, MPH, of the University of California San Diego Medical Center. Dr. Hill described the 2007 wildfires in San Diego, which led to the largest evacuation in California history. The public surveillance system data reporting took place via the Centers for Disease Control and Prevention's (CDC's) BioSense system from six of San Diego's 19 hospitals; data were also gathered from 413 emergency departments around the U.S. These data were used to alert public health officials to emerging disease trends specific to this disaster (respiratory and gastrointestinal) and facilitated post-disaster health surveillance.

For local public health agencies, CI can advance surveillance efforts by providing ways to link clinical lab data directly to agency databases, thus establishing a direct reporting mechanism and surveillance system for monitoring infectious diseases. CI could also enable streamlined reporting between state and local public health departments and the CDC, thereby accelerating access to key databases such as immunization registries. CI might even have a significant impact on bioterrorism initiatives by automated monitoring of incoming data and 911 calls. However, these process improvements are labor intensive and require cooperation on individual and community systems levels. Public health agencies share a similar need for standardized methodologies for data collection and universal coding, as well as for collaborative information sharing across regions.

Reducing Fragmentation within Clinical Trials. The creation of CI represents an opportunity to eliminate inefficiencies in scientific methods that hamper current clinical trials, and to more efficiently and effectively utilizes research findings. CI has the potential to equalize access to care, particularly cancer prevention and screening across regions and around the globe. "Cyberinfrastructure can increase the efficiency, effectiveness, geographic reach, and overall quality of clinical research in an effort toward earlier detection and prevention of cancer across

geographically disparate locations," noted Douglas C. Stahl, PhD, vice president of clinical research operations at City of Hope National Medical Center, an NCI-designated Comprehensive Cancer Center. One area ripe for CI's impact is clinical trials. As Stahl notes, "The approval process is fragmented and problems are advancing faster than solutions." Participation in trials must be increased and the overall clinical trial process accelerated. However, NCI must overcome challenges created by the complex process of initiating trials – particularly the fragmented nature of trials and the lack of supporting technology solutions. Dr. Stahl noted that CI could help resolve this fragmentation by accelerating the process, reducing costs, and streamlining regulatory compliance.

Panel: Federal Directions in Supporting Cyberinfrastructure for Public Health and Health Services

Federal Funding panelists suggested future directions for collaborative research within the public health and health services fields, providing examples of current gaps and future funding. Recent legislative advances point to increased Health IT adoption by diverse healthcare sectors. As seen in recent funding opportunities generated from the American Recovery and Reinvestment Act of 2009 (ARRA) (e.g., Comparative Effectiveness Research (CER) and Strategic Health IT Advanced Research Projects (SHARP)), federal funders are leveraging the confluence of adoption and research to develop an expansive, yet targeted, foundation of evidence-based research that capitalizes on the benefits of CI for public health and health services. (Appendix B provides an overview of federal funding agencies facilitating CI research in the health sector.)

Federal Funding Goals

Federal funders expressed interest in facilitating development of a data collection system that is open, extensible, and scalable. A range of CI related federal activities were discussed, including those focused on partnerships and interoperability, open source technology, workable standards development, and Health IT and quality improvements.

Partnerships and Interoperability. Federal funding agencies are increasingly interested in promoting interoperability and partnerships across stakeholder groups. Emphasis is placed on establishing and developing interoperable systems, improving efficiency, linking research and care, and promoting continuity of care.

- *Interagency Partnerships.* Interagency coordination is imperative. Achieving such coordination requires overcoming differences in cultural and operational traditions, as well as shifting from competitive forces to collaborative synergies. Abdul R. Shaikh, PhD, MHSc, program director, Health Communication and Informatics Research Branch, NCI, mentioned that NCI has initiated a second round of communications research into how existing infrastructure can be used more efficiently. NCI is working with NSF on projects ranging from consumer health informatics to data sharing and computational analytics that emphasize using CI for population health research and practice. Greater emphasis should also be placed on integrating behavioral and population health science with genomics, proteomics, and biomedical sciences.
- *Public-Private Partnerships.* Federal funders reviewed the structure of EHRs, to underscore the importance of public-private partnerships. Dr. Shaikh noted that synergies should be developed between public- and private-sector investments in CI: "[NCI] is reaching out to other stakeholders such as GE Health, Google, Intel, and Microsoft to seek ways to share and aggregate resources and to find new ways to mine and use health data from multiple sources."

Another example described how HMOs in the CRN are working with health providers to resolve cancer-related health information-sharing issues between systems.

- *Regional Partnerships.* Public health funding through the CDC has focused primarily on terrorism and disease-outbreak preparedness. From a Health IT standpoint, funding is focused on interoperability across various health domains. However, the majority of funding through the CDC is state-based and categorical, which presents several unique challenges in achieving interoperability. The foremost challenge is that data continue to be collected in silos. Furthermore, there is little consistency in the storage and management of collected data. This makes it challenging to achieve CDC's objectives of utilizing increased data collection to advance knowledge of public health crises and decrease response time.
- *Public Health and Health Services Partnerships.* The separation between public health (as represented by CDC) and clinical research (as represented by NIH) needs bridging to achieve a collaborative spirit for future research. The CDC and NIH recognize that this somewhat artificial chasm undermines current programmatic offerings. The separation between individual-level biomedical research and public and population health can be overcome through smart interoperability measures. The U.S. Department of Health and Human Services (HHS) aggressively promotes widespread adoption of interoperable EHRs and other Health IT systems to improve quality and efficiency across the care continuum. When research and care are linked through interoperable systems, researchers and practitioners can utilize patient data from clinical encounters to track health trends and outcomes for public health benefit. Researchers should study how to link PHRs to create nationwide networks and standards development through an open and transparent process.
- *Open Source Technology.* Open source technology is critical to CDC's future funding, particularly for workforce development. Open source platforms have the potential to facilitate the movement of data out of silos into more transparent information sharing; this allows links to be established between clinical healthcare and public policy, more effectively delivering timely and critical information to the public. Jason Bonander, MA, director of CDC's Division of Knowledge Management Services, observed, "Open source technologies will advance CDC's interests in biosurveillance, such as what may be possible through the introduction of consumer-facing applications such as Google Health that facilitate the sharing of medical and personal health data."

Future HHS funding will focus on achieving interoperability and establishing standards, as well as emphasizing transdisciplinary and transparent connectivity. Without these elements, Dr. Hesse noted that the silos currently separating provider, personal, and population health data will not be eliminated. Progress is being made in federal support for open source software, with the Office of the National Coordinator (ONC) recent releasing an open source software solution to provide an interoperable and standardized means of sharing health data within and among organizations. [7]

Workable Standards Development. The CDC is developing workable standards for the use of EHR data for situational awareness and surveillance. The agency will focus its funding on developing the ability to use population health data within and between public health jurisdictions, in order to move the application of public health knowledge to the point of care in terms of alerts, reminders, and health information exchange. The data may also be used between public health and individuals, for example, through the creation of personal health information management systems and "sentinel citizens." In these systems, consumers (sentinel citizens) control the flow of health data to CDC for

use in population health decisions – including data used for early outbreak detection and subsequent prevention of widespread outbreaks.

Health IT and Quality Improvements. Funding opportunities in the Agency for Healthcare Research and Quality (AHRQ) were discussed as they target career development and dissertation research grants, small research grants on improving quality through Health IT, exploratory and development grants on quality, and the use of Health IT to improve healthcare quality and outcomes. The goal of these efforts is to learn best practices for changing and improving healthcare with Health IT, especially regarding quality and safety, providing incentives for Health IT implementation, and identifying leaders in the charge for coordination and continuity of care (i.e., the clinical quarterback). J. Michael Fitzmaurice, PhD, Senior Science Advisor for Information Technology in the Office of the director in AHRQ, commented that AHRQ-funded research will examine the technology that supports new clinical and administrative workflows, and will work to determine which infrastructures should be adopted and how they should be organized and used in the delivery of health services.

Current Funding Gaps

Federal funding agencies are interested in providing funding for systems research that fosters and enables collaborative research efforts. However, funders at the symposium expressed that there was slow progress toward a truly interoperable system and noted that more strategic thinking is required to effect change. The panelists recognized a need to reduce the silo structure of programs and offerings by spreading investments across a coordinated spectrum of activities ranging from basic research through operational deployment. It was also noted that federal funders should advocate programmatic offerings that blend health services and public health research. According to Dr. Atkins, agencies should strive to provide leadership by funding programs and solicitations that not only encourage focus, integration, and a functional goal orientation, but also avoid over-specified approaches and solutions that stifle innovation.

Panel: Dissemination of Research on Cyberinfrastructure for Public Health and Health Services

The Publications Panel outlined best methods for communicating the importance of CI in public health and health services to policy makers, to each other, and to the general public. The panel identified new dissemination opportunities such as the rise of social media, information sharing, and new vehicles for publication; and challenges such as the dearth of Health IT journals, information exchange issues, electronic publishing and its effect on journals, and the social and technical challenges inherent in electronic media.

Publishers, like funders, have an important role in establishing the validity of a new transdisciplinary field and sanctioning a style of action-oriented research that will advance the goals of CI in public health and health services. Through the publication of special issues, invited papers, and broad editorial policies, journals and peer-reviewed publications can help mobilize research and practitioner communities to increase awareness and stimulate collaboration. “By providing quality control and vetting information through a credible peer review process, journals and publications will bring value to the dissemination of information on the advancement of CI,” commented Edward H. Shortliffe, MD, PhD, president and CEO of AMIA. Panelists mentioned the need for a new economic model for publications and noted that the dynamic changes occurring in publishing today are due, in part, to the advent of electronic publishing.

Social Media and New Vehicles for Dissemination. "By embracing the rise in social media, journals and publications can provide another source of intersection between the medical, research, and academic communities," said Dr. Shortliffe. Perhaps the most significant contribution journals can make to the discussion and development of CI is publishing articles about integrating domains and disciplines and promoting organizational collaboration. Other valuable journal activities include support for convening expert roundtables and workshops on Health IT. These activities can facilitate information sharing across public health and health service disciplines, in order to gain knowledge from innovations and lessons learned in both fields.

More new vehicles for publication should be developed, said Cynthia M. LeRouge, PhD, assistant professor in the Department of Decision Sciences and Management Information Systems, at St. Louis University. New dissemination vehicles could create a space for topics of special interest and assist in disseminating research findings. By utilizing multiple methods to present and disseminate information, publishers can increase access to and availability of information about CI within the health sector, thus advancing policy and facilitating dialogue.

Challenges to Overcome. The primary challenge encountered by CI researchers is the dearth of journals focused on Health IT, as well as the lack of experts with a specialized interest in CI in public health who are willing to serve as reviewers and editors. Dr. LeRouge commented, "The door is open for change. By addressing these weaknesses, publications can step up and play a significant role in advancing the CI in public health." Dr. LeRouge described a current opportunity for guest editors to focus on articles that integrate literature across domains and disciplines, especially behavioral social aspects and the importance of transdisciplinary work.

Electronic publishing touches on the very social and technical challenges found in research and practitioner settings. The relationship between published knowledge and the infrastructure used to access that knowledge can create interesting issues regarding publication vis-à-vis other means of communicating that knowledge; CI can reduce the time lag that often occurs between research completion and its availability to the community. In this sense, CI could radically change our approaches to communicating knowledge about public health and health services. Still, Kevin Patrick, MD, MS, professor of family and preventive medicine at the University of California, San Diego, and editor-in-chief of the *American Journal of Preventive Medicine*, noted that editors will remain important as curators of this knowledge base, and described their role: to "shed light, take heat, and to give heat."

RECOMMENDATIONS AND NEXT STEPS

The symposium enabled participants to prioritize three key directions:

1) To identify the key dynamics for executing and utilizing CI nationally in public health and health services by applying Atkins' concept of "use-inspired" research;
2) To examine the dynamics of transdisciplinary collaboration across stakeholders and disciplines in order to formulate a variety of partnerships promoting CI research, practice, and dissemination; and
3) To discuss future directions in CI research by reviewing key thematic topics such as EHRs, PHRs, access to care, and patient-inspired systems.

Apply Use-Inspired Research for Health Cyberinfrastructure

Symposium participants reviewed the nature of CI, its technical and social aspects, its theoretical and applied research base, and the systems and organizations surrounding it. They highlighted the need to define CI, determine its scope, and develop a research agenda. Executing and utilizing CI in public health and health services requires principles organized around delivering value to consumers, such as applying Pasteur's Quadrant of "use-inspired" research. Use-inspired research draws on a combination of multiple disciplines, funding agencies, and journals to develop CI systems that improve health and the understanding between public health and health services.

The symposium elicited suggestions about methods for examining connections between public health and health services. Sharing existing data, methodologies, and lessons learned across public health and health services disciplines is essential for promoting ubiquitous and robust CI systems in the health services sector. Stakeholders who provide care or conduct research under the public health umbrella should understand that the data they collect will be shared for research and trend identification to benefit the health field. Participants also identified a need to facilitate gathering and sharing population-based data to formulate public health policy on infectious and chronic diseases.

Kaiser's PHR exemplifies a system that is designed for individual level access, but provides population-relevant statistics. Collaboration between CDC and practitioner public health surveillance systems could yield benefits in terms of systems improvements as well as data mining and sharing. Future research should reflect the Pasteur's Quadrant concept of use-inspired approaches, promoting models and systems that share information, and providing avenues for stakeholders to share their perspectives and enact their solutions.

Identify and Enact New Forms of Collaboration

Dr. Horan stated, "The dimension of timeliness in delivering healthcare is as important as the dimension of quality. Achieving alignment requires a collaboration of public health stakeholders." After examining the dynamics of collaboration across stakeholders and disciplines, participants highlighted the importance of forging partnerships to promote CI research, practice, and dissemination. Symposium participants recommended expanding stakeholder groups. Four types of partnerships were identified: 1) technical and social researchers; 2) practitioners and researchers; 3) public health and health services; and 4) researchers, funders, and disseminators. Forming multidisciplinary teams of researchers, practitioners, funders, and disseminators will help CI move beyond the current research silos, increasing exchange and collaboration to exert a greater influence on public health and health services. Collaboration is primarily visualized as occurring between and among academics, practitioners, and funders. However, there is a larger community of interested parties including consumers and Health IT technologists. Participants noted that connecting these various stakeholder groups would yield more efficient and effective systems and hold great potential for impacting collaboration and a transdisciplinary and expanded network of interested parties.

Bringing together a variety of stakeholders can reduce the current disconnect between public health and health services, as well as between the population and individual levels of care. Due to the interrelationship of these two sectors, participants advocated increased information sharing and collaboration between transdisciplinary integrative research teams. The next key step in stakeholder inclusion will be reviewing the role of practitioner education and incentives. Atkins cautioned funders to resist the urge to perpetuate "islands of innovation and instead form continents of ubiquitous and functionally complete services. Collaboration will involve research communities

who listen humbly to the needs and capabilities of each other and humble ourselves and our disciplinary interests to a collective greater win."

Develop Future Research Directions

EHR and PHR Development. EHRs and PHRs can facilitate efforts to reduce the gaps between individual point of care and public health. EHRs and PHRs and also produce informatics systems that enable theoretical and applied research to converge at a use-inspired focus. The systems cannot perform this task without enhanced interoperability, which federal funders have increasingly advocated in their various funding initiatives, such as the upcoming ARRA programs in Beacon Communities.

Interoperability, Open Source Technology, Workable Standards, Health IT, and Quality. Federal funding goals support future research that promotes: increased data sharing and interoperability across existing and future systems, workable standards, open source technology, and partnerships across diverse groups. Using models such as those described by CDC surveillance and Kaiser Permanente, researchers, practitioners, and funders can focus on integration and interoperability in the context of EHRs and PHRs. Disseminators can provide avenues to publish new work and establish its validity, as well promote information exchange.

Access to Technology and Health Disparities. The local socioeconomic context plays a large role in access to and interpretation of health information and services. CI can enable patients to have increased access to care. However, not all populations can be reached in the same manner, and environmental factors may alter the impact of this access. Future research should look at ways of increasing access to health services for underserved populations, determining why access is low, and formulating population-specific methods to improve access. Symposium participants highlighted the need to pay special attention to the underinsured and uninsured, to understand the existing limitations, and to develop solutions for reaching patients.

New Protocols for Data Sharing. Reform will require innovations in the way data are shared, accessed, communicated, analyzed, and used by the public health and health services fields. Such innovations would improve anticipation of and response times to developing health issues, potentially averting catastrophic health events and crises. Researchers and practitioners should collaborate to determine best practices for data collection, analysis, and sharing. Funding agencies should support data sharing through funding mechanisms that promote interoperability. By bringing an understanding of what already exists and of potential synergies between disparate groups, CI can advance public health and health services, and accelerate data use to benefit health outcomes.

Patient Inspired Systems. Panelists commented on the concept of CI as both a technical and social entity. Technology functions not solely in the passive intake of information, but has the capacity to promote changes in health behavior; thus, researchers should study the role of human-technology interactions in modifying health behavior. Workflow studies that review organizational and human aspects of technology and informatics implementation and use are also essential to CI adoption. In the future, research should incorporate the human element or, as Atkins noted, "the collaboration, not just computation" aspect of CI. To this end, studies need to address the synergies between humans and technologies and develop methods to understand how information is interpreted.

CONCLUDING OBSERVATIONS

Symposium participants provided a framework for an ecosystem of partnerships ranging from practitioners and researchers, to public health and health services, to funders, researchers, and

disseminators. These nascent partnerships are beginning to influence future research directions. Several federal funding agencies and programs are facilitating the role of CI in public health and health services research. NSF's Office of Cyberinfrastructure is a testament to changes in federal funding goals, as the recent NSF grant initiative on cyberinfrastructure for health seeks to create new technologies to accelerate discovery for public health benefit. Additionally, NCI/NIH recently issued a challenge grant request for proposals that directly address CI. HICSS also offers a Cyberinfrastructure for Public Health and Health Services minitrack, as well as dissemination opportunities through symposium papers, white papers, and special journal issues. William G. Chismar, PhD, associate dean for academic affairs, University of Hawai'i, observed, "HICSS is specifically designed as a forum for addressing complex and important health issues such as cyberinfrastructure."

The Health CI research community should embrace the Pasteur's Quadrant concept of use-inspired research: active collaboration with and across stakeholders, promotion of models and systems that share information, and avenues through which interested groups can share their perspectives. CI holds the promise of bridging the gap between public health and health services, building partnerships between disciplines and sectors, and exploring the connections between technical and social dynamics inherent in informatics and particular to health. Most importantly, CI must be viewed through the lens of social interaction, incorporating user interpretation of data, workflow studies, and organizational idiosyncrasies. By building strategic partnerships across agencies, disciplines, and institutions, CI research can link informational and collaborative islands to promote robust, ubiquitous, and effective health delivery and public health systems.

APPENDIX A: AGENDA

HICSS-42 Cyberinfrastructure for Public Health and Health Services: Research and Funding Directions

January 5, 2009 9:00am – 3:45pm

(Includes Lunch)

Join funders, researchers, editors, and leaders in improving health care with informatics at this pre-conference symposium to be held in conjunction with the 42nd meeting of the Hawaii International Conference on System Sciences (HICSS). This symposium will explore the innovations in information systems development and the subsequent opportunities toward making significant advances in public health and health systems research by taking the broad concept of cyberinfrastructure and adapting it to the contextual environment of public health and e-health services.

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Symposium Co-Chairs: Dr. Thomas Horan, Dr. Bradford Hesse, Dr. William Chismar
Symposium Program Chair and Contact: Sue Feldman at Sue.Feldman@cgu.edu

9:00 – 9:15 – Welcome	
Tom Horan	Director, Kay Center for E-Health Research, Assoc. Prof. , Claremont Graduate University
Brad Hesse	Chief, Health Communication and Informatics Research Branch, NCI
Bill Chismar	Associate Dean, University of Hawaii
9:15 – 9:30 – Opening Remarks	
Dan Atkins	Professor, University of Michigan, Ann Arbor, Assoc. VP Research Cyberinfrastructure
9:30 – 10:30 – Funders' Panel	
Jason Bonander	Associate Director, Health Informatics Strategy, CDC
Abdul Shaikh	Program Director, Health Communication and Informatics Research Branch, NCI
Mike Fitzmaurice	Senior Science Advisor, Information Technology, AHRQ
10:45 – 11:45 – Researchers' Panel	
M. Chris Gibbons	Associate Director, Johns Hopkins Urban Health Institute (UHI), Director, Center for Community HEALTH (CCH), Assistant Professor of Public Health and Medicine
Patti Brennan	Professor of Nursing and Industrial Engineering, Chair, Dept. of Industrial and Systems Engineering, University of Wisconsin-Madison
Noshir Contractor	Professor & Director of Science of Networks in Comm. (SONIC) lab, Northwestern Univ.
Dan Atkins	Professor, University of Michigan, Ann Arbor, Assoc. VP Research Cyberinfrastructure
12:45 – 1:45 – Practitioners' Panel	
Doug Stahl	VP Clinical Research Operations, City of Hope
Linda Hill	Director, Preventive Medicine Residency, UCSD Medical Center
Tom Vogt	Senior Investigator, The Center for Health Research, Kaiser Permanente
Kate Christensen	Medical Director, Internet Services Group, Kaiser Permanente
1:45 – 2:45 – Journal and Publication Opportunities	
Kevin Patrick	Professor of Family and Preventive Medicine, UCSD
Janice Nall	Director, Division of E-Health Marketing, CDC
Ted Shortliffe	Editor-in-Chief, Journal of Biomedical Informatics, President Designée, AMIA
Cynthia LeRouge	Associate Professor, St. Louis University, Guest Editor Special Edition, JAIS
2:45 – 3:45 – Synthesis and Next Steps	
Tom Horan	Director, Kay Center for E-Health Research, Assoc. Prof. , Claremont Graduate University
Brad Hesse	Chief, Health Communication and Informatics Research Branch, NCI
Bill Chismar	Associate Dean, University of Hawaii

http://cancercontrol.cancer.gov/hcirb/

HICSS Website: www.hicss.hawaii.edu

http://kaycenter.cgu.edu

APPENDIX B: FEDERAL FUNDING OVERVIEW

The National Science Foundation (NSF) has established the Office of Cyberinfrastructure (OCI) to coordinate and support the acquisition, development, and provision of state-of-the-art cyberinfrastructure resources, tools, and services for conducting 21st century science and engineering research and education. The goal of the OCI is to provide ubiquitous access and enhanced usability in these areas. [8]

The Department of Health & Human Services (HHS), Office of the National Coordinator (ONC), has promoted the Nationwide Health Information Network (NHIN) to provide a secure, nationwide, interoperable health information infrastructure that, at maximum capacity, will connect providers, consumers, and others involved in supporting health and healthcare. [9] The standards, base technologies, and policies that frame the NHIN are developed through open and transparent processes.

The Centers for Disease Control and Prevention (CDC) has established a national initiative called the Public Health Information Network (PHIN) to improve the capability of public health to use and exchange information electronically by promoting the use of standards and defining functional and technical requirements. The PHIN strives to improve public health by enhancing research and practice through best practices related to efficient, effective, and interoperable public health information systems. [10] By collecting surveillance data based on a framework of defined functions, standards, and certified systems in each state and/or local jurisdiction, the CDC can analyze and evaluate metrics to determine the effectiveness of public health initiatives in many areas, including preparedness and outbreak management.

NCI seeks to improve the quality of life of cancer survivors and reduce suffering and death associated with cancer. With a focus on social and behavioral health sciences specifically for the prevention and control of cancer, NCI's efforts are based on the concept of multidimensional and transdisciplinary research, emphasizing fundamental and surveillance research as well as information dissemination and program delivery. NCI funds not only biomedical or clinical care/oncology projects, but also research with broader and transdisciplinary perspectives including behavioral science as well as the prevention and treatment of cancer and other diseases.

The Agency for Healthcare Research and Quality (AHRQ) seeks to improve the quality, safety, efficiency, and effectiveness of the nation's healthcare system, funding research on long-term and system-wide improvements. Research is guided by four specific hypotheses: 1) patient care would be improved if physicians could access comprehensive medical information; 2) improved coordination of care is dependent upon improved information coordination and sharing; 3) information technology can support improved health and health outcomes; and 4) Health IT implementation must be better understood. AHRQ supports the exploration of these hypotheses by funding planning grants, implementation and demonstration grants, research grants, regional health information organization (RHIO) contracts, and National Resource Center contracts.

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