Cyberinfrastructure for Consumer Health

Abdul R. Shaikh, PhD, MHSc, Irene Prabhu Das, PhD, Cynthia A. Vinson, MPA, Bonnie Spring, PhD, ABPP

Introduction

The rapid evolution of cyberinfrastructure has had a transformative effect on the global health enterprise, blurring the boundaries between research and practice in biomedicine, health services, and public health.[1] Commercial and government-supported entities are combining new technologies with behavioral science to monitor social, behavioral, and medical data with other data sources including GIS in the home and clinic to detect disease before manifestation, and to support compliance, treatment, and health promotion. Nowhere is this more evident than in the U.S., where the public- and private-sector development of health-related platforms, tools, and applications, and the electronic information infrastructure to connect them, are being supported by key policy, regulatory, and market-driven innovations.[2,3]

Fundamental to the theme of this supplement to the *American Journal of Preventive Medicine* on Cyberinfrastructure for Consumer Health are the concepts of cyberinfrastructure and health information technology (HIT). Incorporating concepts that include high-performance computing, parallel computing, and cloud computing, cyberinfrastructure is related to the broader conceptualization of network and information technologies that include systems, tools, devices, and applications based on supercomputing systems, distributed networks, cloud computing, and information management enabled by federal government investment in electronic information infrastructure over the past decades.[4–6]

Consumer health informatics refers to HIT that utilizes data enabled by cyberinfrastructure, or in other words the computer, mobile, and Internet platforms necessary for coordinating care delivery by health systems and clinical and public health professionals, as well as for consumers to be empowered to manage their own health.[7,8] Electronic tools may be used to share timely, important medical information across clinical settings as well as to facilitate communication among clinicians, patients, and their caregiver network. Thus, HIT for consumer health can enable coordinated care, information access, and the improved awareness and use of resources tailored to the context of the individual while based on data informed by the health of the population.

The articles included in this supplement[9–30] stem from a series of symposia exploring key opportunities and challenges in utilizing informatics platforms and technologies for advancing population science, medicine, and consumer health. Convened by the National Cancer Institute (NCI) in collaboration with government, private sector, and academic partners, the symposia focused on research, practice, and policy implications of HIT in the context of the evolving national priorities for improved care delivery and population health. This supplement will be released in concert with a related special issue in the Society of Behavioral Medicine's new online journal *Translational Behavioral Medicine,* which will examine how information technology can be applied to behavioral medicine practice and policy.[31]

A Conceptual Framework for Cyberinfrastructure for Consumer Health

The conceptual framework that provides a population health context for cyberinfrastructure and consumer health is presented as Figure 1. Beginning on the left side of the diagram, the *information ecology* represents the petabytes of diverse and complex data collected, stored, managed, and shared in the broader information environment; both established and more recent sources of health-related information, and the flow of information between individuals and institutions are implied in this conceptualization of data.[32] Established *data sources* are those data that are recognized as integral sources for health information exchange using information technology mechanisms. These data sources include population surveillance systems (e.g., the NCI Health Information

From the Health Communication and Informatics Research Branch, Behavioral Research Program (Shaikh), the Outcomes Research Branch, Applied Research Program (Prabhu Das), Division of Cancer Control and Population Sciences (Vinson), National Cancer Institute, NIH, Bethesda, Maryland; and the Department of Preventive Medicine, Psychology, and Psychiatry, Northwestern University (Spring), Chicago, Illinois

Address correspondence to: Abdul R. Shaikh, PhD, MHSc, Health Communication and Informatics Research Branch, Behavioral Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, EPN 4062, 6130 Executive Boulevard, Bethesda MD 20892. E-mail: shaikhab@mail.nih.gov.

0749-3797/$17.00
doi: 10.1016/j.amepre.2011.02.012

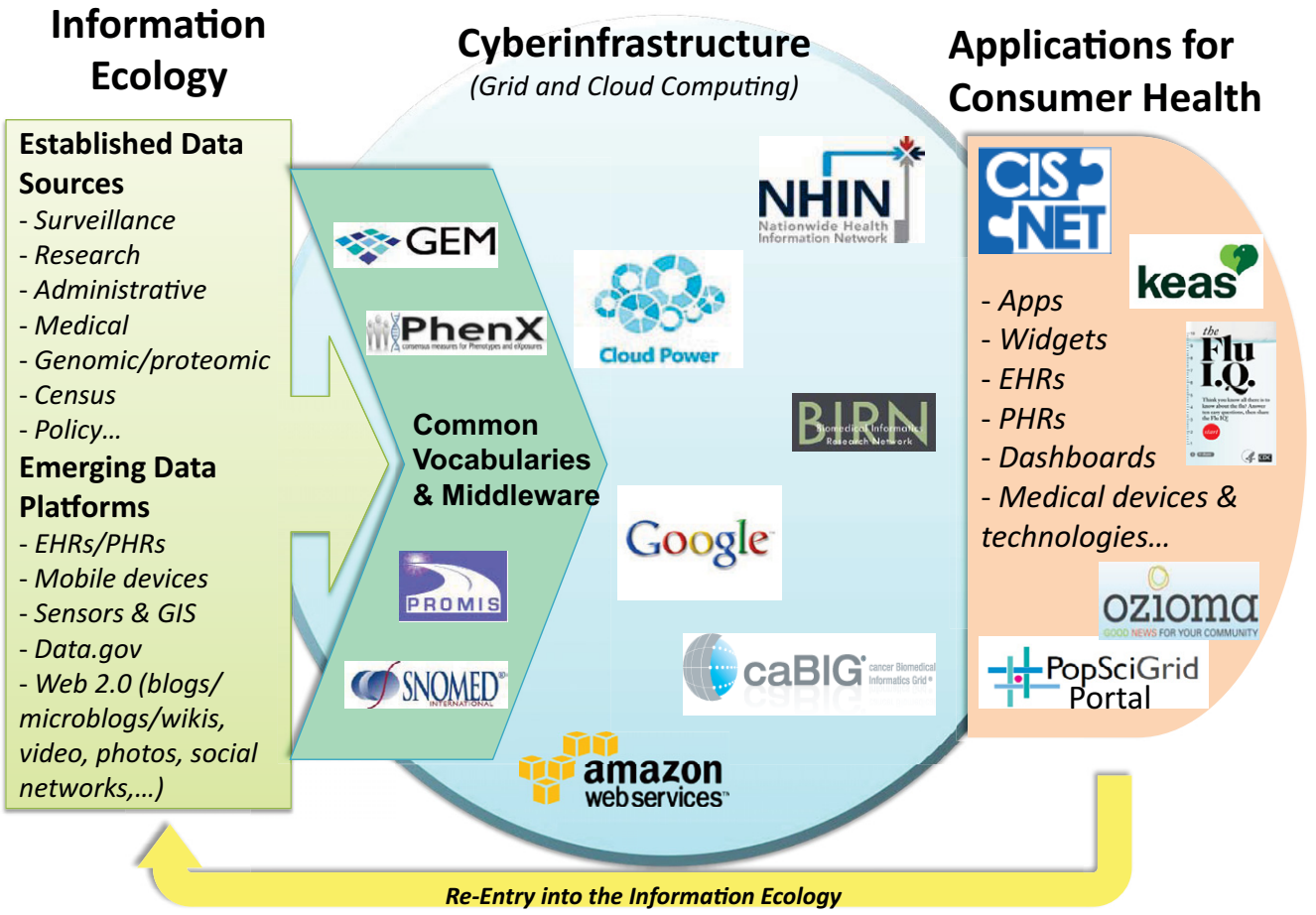

Figure 1. Conceptual framework for cyberinfrastructure for consumer health
EHR, electronic health record; PHR, personal health record

National Trends Survey, state cancer registries); health-related research (e.g., clinical trials, behavioral interventions, cancer survivorship studies); administrative and health systems (e.g., health utilization, claims), medical, genomic/proteomic, census, and policy data that are often not available or difficult to access in electronic formats. Conversely, *emerging data* refer to more recent mechanisms and systems of producing, sharing, and accessing data including electronic health records (EHRs) and personal health records (PHRs); data from mobile networks and devices such as smartphones, sensors, and GIS; and Web 2.0, which is defined as applications and websites that provide user-generated content (e.g., social networks, blogs, and wikis).

Common vocabularies and *middleware* refer to applications, systems, and initiatives designed to facilitate the potential translation, harmonization, and access to electronic data such as health information exchanges that integrate and provide health-related information in clinical settings,[13] and Systematized Nomenclature of Medicine—Clinical Terms (SNOMED CT®). Other examples described in this supplement include some innovative initiatives for encouraging standardized measures for health-related data such as the Grid Enabled Measures (GEM) database[14] and PhenX.[15]

The middleware applications and systems and the data they help translate and harmonize are accessed and utilized using the networks and information technologies that make up the global cyberinfrastructure. Various instantiations of cyberinfrastructure include both grid-computing networks such as the Biomedical Informatics Research Network (BIRN) and the cancer Biomedical Informatics Grid (caBIG®), and cloud-based systems provided by commercial vendors including Amazon, Google, and Microsoft.

Consequently, these data can be utilized in various clinical and public health *applications for consumer health*, such as EHRs and PHRs. The Keas online helper system,[29] the Comprehensive Health Enhancement Support System (CHESS),[24] and the HealthATM concept for underserved populations[12] are three applications that are presented in this supplement. Another important aspect of the framework is that, through their use, these applications for consumer health also

contribute data back into the broader information ecology as evidenced by the inclusion of EHRs in both the data and application constructs.

The Federal Context and Related Symposia

The IOM's vision for twenty-first century health care embraces the effective use of HIT to bridge the "healthcare–IT chasm," analogous to the quality of healthcare chasm highlighted by the IOM in the 2001 report of the same name. Responding to the challenges posed by HIT and the electronic information environment, the federal government's national HIT strategic plan has focused on two primary goals: enabling patient-centered care and optimizing population health research and practice. Both goals are predicated on the notion of appropriate access to and sharing of electronic health information through a national health information infrastructure.[33]

The timely release of two President's Council of Advisors on Science and Technology (PCAST) reports[2,34] in 2010 echo the central focus of this special supplement by addressing the promise and challenge of HIT and cyberinfrastructure (or network and information technology) for population health. HIT's potential for improving national health outcomes while reducing the burgeoning cost of health care is tied to key pieces of legislation including the Patient Protection and Affordable Care Act (ACA) and the Health Information Technology for Economic and Clinical Health (HITECH) Act, part of the American Recovery and Reinvestment Act of 2009 (ARRA), which support the development of HIT and the creation of a national healthcare infrastructure.

The essence of the PCAST report[2] on network and information technology centers on the notion of **big data**, referring to how rapid advances in cyberinfrastructure and HIT are driving the emergence of a new transdisciplinary science linking agencies such as the National Science Foundation (NSF) and NIH to extract knowledge from health-related data.[35] The report also describes three emergent innovations driving cyberinfrastructure for health: (1) comprehensive, lifelong health records that include data from consumers, clinicians, and contextual information from environmental sensors; (2) data liquidity with analytical tools for decision support that are scalable for consumers and professionals; and (3) devices, tools, and applications for personalized health care. HITECH also incorporates the key concept of **meaningful use** of HIT, specifying the criteria providers must meet to receive incentive payments with important implications discussed in this issue on the role of behavioral medicine and patient-facing technologies for consumer health.[20,36]

In response to these policy developments and expert panel recommendations, and given their alignment with the mission of the NCI's Division of Cancer Control and Population Sciences, a series of symposia were convened by the NCI and partner agencies. The first event, in March 2008, was an expert panel Workshop on Cyberinfrastructure in Behavioral Medicine at the University of California, San Diego, with individuals invited to participate because of their potential for contributing innovative ideas representing behavioral science, government, and experts in public health informatics.[37] Co-sponsored by the NSF and informed by the 2003 NSF Blue Ribbon Advisory Panel on Cyberinfrastructure, this workshop focused on the development and potential uses of grid-based computing (e.g., data harmonization, transdisciplinary collaboration, and advanced computation) in behavioral medicine for cancer prevention and control. Participants explored how cyberinfrastructure, and the human and technical infrastructure it supports, can encourage collaboration, data sharing, and greater computational capabilities for supporting a new transformative science of behavioral medicine and population health.

One of the projects tied to this effort is the PopSciGrid Community Health Data Portal, a proof of concept that addresses the DHHS Open Government Plan and Community Health Data Initiative.[38] The PopSciGrid Portal is an evolving platform for visualizing and communicating publically available health-related data for community impact and exploration of innovative avenues of research for cancer prevention and control (http://cancercontrol.cancer.gov/hcirb/cyberinfrastructure/popsci.html). A follow-up workshop was recently convened (2011) to explore research and practice issues related to seeded-cloud approaches to public health cyberinfrastructure for data-intensive computing.[39]

In January 2009 at the 42nd Annual Hawaii International Conference on Systems Science (HICSS), NCI cosponsored a symposium on Cyberinfrastructure for Public Health and Health Services.[40] The event convened researchers, practitioners, funders, and publishers to address three objectives: (1) identify the key factors needed for effective utilization of cyberinfrastructure nationally in public health and health services; (2) examine the dynamics of transdisciplinary collaboration; and (3) develop future directions for harmonization and visualization of data for research, practice, and consumer audiences.

The third event took place in November 2009 when a partnership of federal agencies convened the Informatics for Consumer Health Summit on Communication, Collaboration, and Quality in Potomac MD.[41] This summit developed as a response to the need to disseminate research-tested health informatics interventions and enable utilization by a variety of end users. Bringing to-

gether a diverse group of leaders spanning commercial IT, government, health care, education, research, and advocacy, the summit focused on fostering collaboration for developing evidence-based consumer health IT products that empower providers and enable consumers to gain mastery over their own health.

Organization of the Supplement

A recent meta-definition of *big data* emphasizes the challenges inherent in realizing the full potential of the modern information environment for health: "Data whose size forces us to look beyond the tried-and-true methods (of analysis, storage, distribution, and computation) that are prevalent at that time."[42] In the spirit of this grand challenge, the content of this supplement is targeted at health scientists, policymakers, and practitioners, presenting contributions that address important aspects of HIT and behavioral medicine as potential enablers of consumer-centered health and preventive medicine.

Featuring contributions that span the behavioral and social sciences, medicine, engineering, computer sciences, and systems sciences, the supplement is organized into three sections: perspectives from the federal government; cyberinfrastructure and population health; and consumer health informatics. The second and third sections comprise original research, targeted overviews, policy pieces, and commentaries to address a range of conceptual, theoretical, and applied topics related to cyberinfrastructure and consumer health informatics.

Perspectives from the National Institutes of Health and the National Science Foundation

The first section presents perspectives from the NIH and the NSF that emphasize the integral role of cyberinfrastructure and HIT for advancing biomedical science.[9,10] Part of a broader group of collaborating federal agencies including the Agency for Healthcare Research and Quality (AHRQ), CDC, and the National Institute of Standards and Technology (NIST), both NCI and NSF were integral partners of the aforementioned symposia.

Through implementation of an agency-wide sociotechnical strategy on cyberinfrastructure, NSF in particular has played a leadership role in supporting virtual organizations for transdisciplinary collaboration that transcends traditional scientific, geographic, and institutional boundaries.[6] A similar transformation is currently underway at the NIH. Driven by the need to understand the "cells to society" deluge of health-related electronic data spanning the genomics/proteomics, biomedical, behavioral, and population health disciplines, agency leadership is exploring strategic investment in multi-agency research initiatives for advancing population health.[33] The challenge of understanding and, more importantly, making effective use of this fragmented information environment underscores what the IOM describes as the "structural inability" of conventional medicine to exploit the unprecedented amount of electronic information available at our fingertips.[43] NIH and NSF are thus providing leadership in the digital information age through investment in cyberinfrastructure and HIT that spans the spectrum of health research and practice, from patients and providers to scientists and government entities.[3]

Cyberinfrastructure and Population Health

Findings from the 2009 HICSS symposium presented in the opening paper in this section[11] provide a useful overview of the concept of cyberinfrastructure for health that incorporates scientific discovery and practice across three dimensions: research–practice, health services–public health, and social–technical.

Related to the development of clinical and community information systems in the context of cyberinfrastructure, two papers[12,13] share findings from their exploratory research, the first providing an innovative example of how a cloud-based PHR system called HealthATM could be used to help underserved populations manage their health, while the second examines the development of community-based health information exchanges for providing clinical information to patients and providers. Related examples of efforts to promote standardized measures for the biomedical sciences are presented next; first, using the principles of Web 2.0 and Science 2.0 to accelerate discovery by developing an interactive Internet platform called the Grid-Enabled Measures (GEM) Database to promote standardized measures tied to theoretically based constructs and sharing of related harmonized datasets,[14] and next with a description of two consensus-based approaches to establishing standardized measures for promoting data compatibility in genome-wide association studies (GWAS).[15]

Rounding out this section are a series of commentaries that discuss the promise of mobile health applications as the definitive proof-of-concept for cyberinfrastructure,[16] and a proof-of-concept system dubbed Infovigil that identifies and analyzes health-related information from online sources such as Twitter to demonstrate the utility of infodemiology, an emerging area of research in public health informatics.[17] The penultimate paper in this section discusses the importance of systems science methodologies for making sense of the vast amounts of data afforded by cyberinfrastructure.[18]

Consumer Health Informatics

The final section of the supplement—consumer health informatics—is introduced with a general discussion of the importance of organizing technologies according to meaningful-use categories and related challenges that will enable patients to engage in their own health care.[20] Both research and conceptual papers elaborate on the various dimensions of consumer health informatics, ranging from usability and accessibility,[22,23] measurement of cancer care,[24] application of informatics in decision making regarding palliation and hospice care,[21,25,26] and integration within the patient-centered medical home.[27] A late-breaking commentary shares findings from a related NIH–academic–industry workshop on the challenges and drivers for improving patient outcomes and personalizing care while reducing costs in the development of intelligent healthcare systems.[19]

Unique contributions are provided by an advocate[28] and an inventor[29] of health technology systems and products. The consumer health informatics perspective brings home the message about the needs discussed throughout this supplement: The health of the population will be well served when the use of computer technology is an integral part of the health care of each individual within that population. Critical to effectively establishing a transformative healthcare system is assuring that HIT programs, platforms, and processes benefit the end user to achieve meaningful use. Otherwise, efforts to design, test, and implement HIT systems will not succeed in improving individual and population health.

The final paper in the supplement[30] explores the promise and challenge presented by the rapid evolution of cyberinfrastructure and HIT to bridge health and communication inequalities. Addressing these widespread and persistent disparities will involve careful planning and investment from public, private, and community-based partners.

Conclusion

The breadth of relevant, thought-provoking research, case studies, and commentaries assembled in this issue highlight gaps and opportunities for policy, practice, and research in behavioral, health services, and consumer health informatics. This supplement's intent is to promote further dialogue and encourage the development of collaborative, transdisciplinary research and practice initiatives that span the behavioral, social, biomedical, computer science, engineering, and informatics communities.

Continued advances in health information technology and cloud- and grid-based data infrastructures are transforming health-related research, practice, and policy. Consequently, research that effectively utilizes cyberinfrastructure, a comprehensive online environment for data harmonization and sharing, transdisciplinary collaboration, and advanced computational methods, can accommodate data from "cells to society" to accelerate knowledge discovery and transform population science and consumer health.

Publication of this article was supported by the National Institutes of Health.

No financial disclosures were reported by the authors of this paper.

References

1. Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington: National Academies Press, 2001.
2. President's Council of Advisors on Science and Technology. Designing a digital future: federally funded research and development in networking and information technology. Washington: Executive Office of the President, 2010.
3. Stead WW, Lin HS, Eds. Computational technology for effective health care: immediate steps and strategic directions. Washington: National Academies Press, 2009.
4. National Research Council. Evolving the high performance computing and communications initiative to support the nation's information infrastructure. Washington: National Academies Press, 1995.
5. National Research Council. Innovation in information technology. Washington: National Academies Press, 2003.
6. National Science Foundation. Cyberinfrastructure vision for 21st century discovery. NSF: Arlington VA, 2007. http://www.nsf.gov/pubs/2007/nsf0728/index.jsp?org=NSF.
7. Alamantariotou K, Zisi D. Consumer health informatics and interactive visual learning tools for health. Int J Electron Healthc 2010;5(4):414–24.
8. Marchibroda JM. The impact of health information technology on collaborative chronic care management. J Manag Care Pharm 2008;14(2S):S3–S11.
9. Hesse BW, Croyle RT, Buetow KH. Cyberinfrastructure and the biomedical sciences. Am J Prev Med 2011;40(5S2):S97–S102.
10. Chowdhury FN, Joyce K. Pushing the boundaries of transdisciplinary science through cyber-enabled research. Am J Prev Med 2011;40(5S2):S103–S107.
11. Chismar W, Horan TA, Hesse BW, Feldman SS, Shaikh AR. Health cyberinfrastructure for collaborative use-inspired research and practice. Am J Prev Med 2011;40(5S2):S108–S114.
12. Botts NE, Horan TA, Thoms BP. HealthATM: personal health cyberinfrastructure for underserved populations. Am J Prev Med 2011;40(5S2):S115–S122.
13. Thornewill J, Dowling AF, Cox BA, Esterhay RJ. Information infrastructure for consumer health: a health information exchange stakeholder study. Am J Prev Med 2011;40(5S2):S123–S133.
14. Moser RP, Hesse BW, Shaikh AR, et al. Grid-enabled measures: using Science 2.0 to standardize measures and share data. Am J Prev Med 2011;40(5S2):S134–S143.

15. Schad PA, Mobley LR, Hamilton CM. Building a biomedical cyberinfrastructure for collaborative research. Am J Prev Med 2011;40(5S2):S144–S150.
16. Atienza AA, Patrick K. Mobile health: the killer app for cyberinfrastructure and consumer health. Am J Prev Med 2011; 40(5S2):S151–S153.
17. Eysenbach G. Infodemiology and infoveillance: tracking online health information and cyberbehavior for public health. Am J Prev Med 2011;40(5S2):S154–S158.
18. Mabry PL. Making sense of the data explosion: the promise of systems science. Am J Prev Med 2011;40(5S2):S159–S161.
19. Sairamesh J, Griss ML, Weber PA, et al. Innovation in healthcare intelligence: cross-sector convergence beyond electronic medical records. Am J Prev Med 2011;40(5S2):S234–S237.
20. Ahern DK, Woods SS, Lightowler MC, Finley SW, Houston TK. Promise of and potential for patient-facing technologies to enable meaningful use. Am J Prev Med 2011;40(5S2): S162–S172.
21. Corn M, Gustafson DH, Harris LM, Kutner JS, McFarren AE, Shad AT. Survey of consumer informatics for palliation and hospice care. Am J Prev Med 2011;40(5S2):S173–S178.
22. Jones JB, Shah NR, Bruce CA, Stewart WF. Meaningful use in practice: using patient-specific risk in an electronic health record for shared decision making. Am J Prev Med 2011;40(5S2): S179–S186.
23. Goldberg L, Lide B, Lowry S, et al. Usability and accessibility in consumer health informatics: current trends and future challenges. Am J Prev Med 2011;40(5S2):S187–S197.
24. Clauser SB, Wagner EH, Bowles EJA, Tuzzio L, Greene SM. Improving modern cancer care through information technology. Am J Prev Med 2011;40(5S2):S198–S207.
25. Madhavan S, Sanders AE, Chou W-YS, et al. Pediatric palliative care and eHealth: opportunities for patient-centered care. Am J Prev Med 2011;40(5S2):S208–S216.
26. Abernethy AP, Wheeler JL, Bull J. Development of a health information technology–based data system in community-based hospice and palliative care. Am J Prev Med 2011; 40(5S2):S217–S224.
27. Finkelstein J, Barr MS, Kothari PP, Nace DK, Quinn M. Patient-centered medical home cyberinfrastructure: current and future landscape. Am J Prev Med 2011;40(5S2):S225–S233.
28. Gruman JC. Making health information technology sing for people with chronic conditions. Am J Prev Med 2011;40(5S2): S238–S240.
29. Bosworth A, York C, Kotansky H, Berman MA. An inventor's perspective on consumer health informatics. Am J Prev Med 2011;40(5S2):S241–S244.
30. Viswanath K. Cyberinfrastructure: an extraordinary opportunity to bridge health and communication inequalities? Am J Prev Med 2011;40(5S2):S245–S248.
31. Abernethy AP, Hesse BW (eds). Special section on information technology and evidence implementation. Translational Behavioral Medicine 2011;1(1).
32. Brown JS. The social life of information. Boston MA: Harvard Business Press, 2002.
33. DHHS. Coordinated federal health information technology strategic plan: 2008–2012. The Office of the National Coordinator for Health IT. Washington: DHHS, 2008.
34. President's Council of Advisors on Science and Technology. Realizing the full potential of HIT to improve healthcare for Americans. Washington: Executive Office of the President, 2010.
35. Big data: community cleverness required [editorial]. Nature 2008;455(7209):1. www.nature.com/nature/journal/v455/n7209/full/455001a.html.
36. Office of the National Coordinator for Health Information Technology. Electronic Health Records and Meaningful Use.healthit.hhs.gov/portal/server.pt?open=512&objID=2996&mode=2.
37. Expert Panel Workshop on Cyberinfrastructure in Behavioral Medicine. La Jolla CA, 2008: guest.cvent.com/EVENTS/Info/Summary.aspx?e=69ee1148-d4f7-4dd8-b6e9-876077a50422.
38. DHHS. HHS Open Government Plan Version 1.1. www.hhs.gov/open/plan/opengovernmentplan/index.html.
39. Health Cyberinfrastructure. Seeded Cloud Approach to Cyberinfrastructure for Public Health and Health Services. La Jolla CA: Jan 10–11, 2011. www.healthcyberinfrastructure.org/.
40. Symposium on Cyberinfrastructure for Public Health and Health Services. Research and funding directions, 2009. Big Island, Hawaii. www.hicss.hawaii.edu/hicss_42/swt/CyberinfrastructureHealthAgenda.pdf.
41. Informatics for Consumer Health. 2009 ICH Summit. Potomac MD. informaticsforconsumerhealth.org/index.php?q=content/2009-ich-summit.
42. Jacobs A. The pathologies of big data. Commun ACM 2009; 52(8):36–44.
43. Olsen LA, Aisner D, McGinnis JM, eds. The learning healthcare system: workshop summary. Washington: National Academies of Science Press, 2007.