Lessons Learned from the Shared Pathology Informatics Network (SPIN): A Scalable Network for Translational Research and Public Health

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The article by McMurry et al. in the current issue of JAMIA describes an innovative architecture to support National Health Information Networks (NHIN) that comprises a “. . . distributed approach to data storage in order to protect privacy and enable strong institutional autonomy to engender participation. The architecture provides oversight and transparency to ensure patient trust and allows variable levels of access according to investigator needs and institutional policies, defining a self-scaling architecture that encourages voluntary regional collaborations that coalesce to form a nationwide network . . .”1 This work moves informatics a critical step forward in providing an open architecture that can support translational research and interface with appropriate depth to systems for public health and clinical care. This linkage is crucially important for the sharing of biospecimens, and a valuable resource in this “–omics” era. Modern molecular medicine drives the demand for extensively annotated tissue specimens for basic science and translational research. Availability of such specimens can support and facilitate clinical trials, biomarker development, and discovery of new targets for novel treatments. The test bed used for McMurry’s architecture has been the Shared Pathology Informatics Network (SPIN).2–4 The NIH-funded SPIN project inspired development of a number of very interesting open source technologies. These include tools for: de-identification,5, 6 autocoding,7, 8 and structuring of clinical data for use in tissue banking informatics.9, 10 This demonstrates the potential of interoperable architectures to serve the needs of care providers, investigators, and public health authorities.

A key aspect of the work by McMurry is that their project can successfully “… protect patient privacy, grant institutional autonomy, and exploit legacy systems and data sharing agreements . . .”.1 This work includes successful development, integration, and support for de-identification systems and creation of honest broker mechanisms for the effective delivery of information to users. This addresses a frequently ignored component for the delivery of translational research by providing an effective bridge between the clinical and research communities. Public health needs are frequently ignored in the development of such systems. There is critical need for such services in biosurveillance and public health informatics. The Harvard group’s work ensures “… both national anonymized coverage for routine analysis and provider authorized re-identification during emergency investigations . . .”.1 Hence their scalable architecture provides a multi-faceted and effective solution long sought after in biomedical informatics. It interconnects clinical, translational research, and public health informatics stakeholders.

The recent NIH Roadmap initiative specifically recognizes innovative architectures such as the one proposed by McMurry et al.1 as vital components in advancing the understanding of disease and in improving health.11 Indeed, a trans-NIH Informatics Committee (TNIC) has been established to coordinate all informatics activity under the Roadmap. As one specific example of an NIH Roadmap activity, the National Electronics Clinical Trials and Research (NEC-TAR) network exists to enhance the efficiency of clinical research networks through informatics and other technologies.12 As a result, investigators will more easily broaden the scope of their research.12 A second example is the recently funded cancer Biomedical Informatics Grid (caBIG) project13–16 coordinated by the U.S. National Cancer Institute. The nationwide caBIG investigators group collectively develops and evaluates informatics tools and networks to support cancer research, and specifically translational research. A third Roadmap example is the NIH’s seven recently funded National Centers for Biomedical Computing (NCBC). Two of the NCBC sites focus on translational informatics and a third focuses on biomedical ontology critical to the integration of clinical and research informatics efforts.17
The NIH and other agencies of the Department of Health and Human Services place increasing emphasis on, and ascribe greater significance to informatics research and development activities. The first U.S. National Health Information Technology Coordinator was established in 2004. The President charged the Coordinator with facilitating widespread deployment of health information technology within ten years to realize substantial improvements in health-care safety, quality and efficiency. Translational research will benefit immensely from the national focus on deployment of interoperable systems for health care. The current era has been heralded as the “Decade of Informatics,” as evidenced by the aforementioned national efforts, including adoption of key standards in health care (CDA, HL7, CCOW, LOINC, CDISC, BRIDG and others). The standard-related efforts, as well as corresponding terminologies and ontologies (e.g., UMLS and SNOMED) must be diffusely embedded into software development projects to ensure interoperability. The architecture proposed by McMurry et al. provides significant new opportunities for wide-scale adoption of informatics and research tools.

References


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