

C-D3-04:

Governing Access to a Distributed Research Network's Data Resources

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To answer many public health questions, it is essential to use information from more than one electronic data system, and efficient ways are needed to securely access and use data from multiple organizations while respecting the regulatory, legal, proprietary, and privacy implications of this data use and access. One approach centers on the development of distributed research networks that allow data owners to maintain confidentiality and physical control over their data, while permitting authorized users to ask essential questions. Once such a network is fully operating and key elements are in place, sharable data resources can be made available to approved network users, under approved conditions. For instance, data from a large cohort of hypertensive patients with five years of utilization (a hypertension cohort) could be available on the network. The following questions will need to be addressed: Who can have access? Under what conditions should access be granted? What policies/procedures are required? To address the specific needs associated with governance of a network's resource(s), the authors call for the establishment of user eligibility requirements, policies to deal with funders (i.e., access rules for study funders), clear standard operating procedures, and guidelines for accessing the network. Recommendations to meet to those needs include: 1) establishing data oversight policies; 2) defining responsibilities for data resource access; 3) defining responsibilities for data owners at each site (i.e., responding to queries when requests come in); 4) creating standard operating procedures for the data resource; 5) creating collaboration guidelines for external partners; and 6) monitoring overall resource use. For the purpose of this poster, we propose to illustrate responsibilities for data owners at each site.

PS1-01:

Digital Scholarship: Scientific Publishing at the Crossroads

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Background/Aims: Scholarly communication is the system through which research and other scholarly writings are created, evaluated for quality, disseminated to the scholarly community, and preserved for future use. The traditional formal means of interchange, publication in peer reviewed journals, is at the core of the communication infrastructure. However, the structures and processes by which scholars communicate have undergone a major transformation in recent years with the advent of the digital age. New electronic technologies for access to information appear to be revolutionizing scholarly publishing, aptly defined by the term, digital scholarship. Current trends in the chaotic scholarly publishing market can be perceived as both opportunities for and threats to digital scholarship. **Methods:** Digital scholarship is in a state of unprecedented upheaval as publishers, librarians, legislators, scholarly societies, scientists and other scholars engage in tactics to propel change in directions that promote their individual goals. Strategies involve remodeling the publishing market, modifying academic and research institutional procedures, and influencing public policy. **Results:** Emerging digital publishing technologies, increasing volume of scholarly works, and decreasing satisfaction with a costly and dysfunctional economic model are changing the fundamental structure of scholarly publishing. Research institutions, as well as government and funding agencies, are implementing or exploring strategies which promote free and open access to research results. These include alternative copyright arrangements, e-print archives and digital repositories. **Conclusion:** Scholars, researchers, and society at large gain tremendous benefits from the expanded dissemination of research findings. However, several factors have impeded the progress of digital scholarship, including efforts to protect

publishing revenues and profits, legal licensing restrictions, and the traditional culture of academia. It is therefore critical that the scientific community is actively engaged to ensure that the advancement of scholarship takes priority in the development of new publishing models.

PS1-17:

Developing an Analytical Tool for Assessing the Adequacy of State Health Information Exchange Laws

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Aims: To develop and test an analytic legislative tool that provides states with the ability to analyze and propose reform to laws related to the exchange of electronic health information. **Background:** Through extensive research, the multi-state Harmonizing Security and Privacy Law Collaborative (HSPLC) found myriad barriers to health information exchange in laws and business practices. In some cases, barriers are beneficial because they protect people's privacy. However, barriers can be problematic when they prevent the timely exchange of information needed for the treatment of patients. There are many inconsistencies in state and federal laws and among state statutes in their definitions, organizational structure, and content. Some states have adopted new legislation that addresses the exchange of health information that may further exacerbate differences among states and impede interstate exchange of electronic health information. **Methods:** HSPLC developed a set of analytical tools and a narrative guide, the Roadmap, to assist states in implementing an effective legal framework for the review and adoption of legislation that supports health information exchange (HIE). The tools and Roadmap were created through extensive research to identify best practices for identifying, evaluating, and reforming state laws related to the disclosure of electronic health information. **Results:** HSPLC found that various state resources (legal, legislative, healthcare policy, healthcare providers, and consumers) are necessary for successful completion of the Roadmap to identify opportunities for legislative reform. HSPLC believe that states will have greater likelihood of success in achieving legislative reform if they use the Roadmap and reach out to other states contemplating a change in legislation. Interstate collaboration and coordination are essential if we are to achieve a national legal and technical infrastructure that facilitates health information exchange. **Conclusions:** Legislation in most states does not adequately address the exchange of electronic health information. Drafting of legislation must take into account a state's unique environment and culture, and the needs and support of stakeholders. The goal of using the analytic tool is to protect health information while removing barriers that impede the exchange of vital information. The HSPLC Roadmap provides a step by step process to analyze and reform state legislation.

PS1-28:

Optimizing Health Informatics Interventions From the Patient's Perspective: Focus Group on Improving Safe NSAID Use

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Background: Patient-provider messaging in an electronic medical record (EMR) system provides an opportunity to create and sustain productive patient-provider interactions. We elicited patient perspectives on design, benefits, and concerns to improve usability and efficacy of a proposed health informatics intervention to support surveillance of, and provider feedback on, over the counter (OTC) non-steroidal anti-inflammatory drug (NSAID) use. **Methods:** We conducted four focus groups involving Kaiser Permanente Georgia (KPG) adults 25–70 years old who had a medical condition for which NSAIDs should be used cautiously or had a recent prescription for NSAIDs. The focus group elicited information regarding: OTC NSAID use (including recognition of risks and side effects), design of an OTC NSAID survey to be delivered via KP.Org (the secure KP Internet portal for patient-physician messaging), benefits and concerns about transmission of this information via electronic messaging to their primary care physicians, and