Access to Data for Health Care, Research, and Health Planning

Introduction

Use of clinical information can improve the quality of health care experiences for individuals, expand knowledge about disease and treatment and prevention, improve understanding about the effectiveness and efficiency of health care systems, aid businesses in meeting the needs of their employees and customers, and support public health.

Promoting Access While Protecting Privacy. Protecting patient privacy is a key element in broadening access to data for activities such as research, and health planning. To achieve this goal, all the personnel, systems, and processes engaging in health information storage and exchange within and across organizations should adhere to principles of data stewardship. Data stewardship encompasses the full range of responsibilities and accountabilities associated with any use of personal health information. Several examples of the use of health data are briefly noted below.

- **Comparative Effectiveness.** Comparative effectiveness research is essential to improve health care delivery and quality while monitoring costs. Health care organizations need to reuse extant clinical and demographic information from electronic health records to evaluate current processes and compare different procedures, therapies, and workflows to find what works best for patients.

- **Clinical Research and Trials.** NIH recognized the challenges inherent in bringing research results to the community in a timely manner and created the Clinical and Translational Sciences Awards to move results from bench to bedside. Critical to these efforts is the mining of information to identify candidates for clinical trials and research.

- **Health Information Exchange.** Health information exchange is the transfer of personal health information across organizations to ensure that health care providers have access to all of the relevant information essential to high quality care. Without access to an individual’s complete health information from all sources of care, health care providers are unable to make appropriate clinical decisions in real time at the point of care.

- **Health Services Research.** Health services research focuses on access, organization, costs, and processes of care and effectiveness from a broader view, rather than the individual patient or illness. Reducing medical errors and improving patient safety through health services research is substantially dependent upon aggregated patient data.

- **Quality Measurement and Improvement.** The U. S. must improve the quality of health care. Improving quality requires the use of electronic health records with evidence-based clinical decision support systems to capture information at the point of care. The exchange and reuse of clinical information is essential to improved care across the continuum of providers and care settings.

- **Public Health, Prevention, and Monitoring.** Ensuring the health of the public requires ongoing monitoring of emerging infectious diseases and reportable conditions. Access to aggregated patient data is critical for health promotion, health planning, and the protection of the public.

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