Health Data Use, Stewardship, and Governance: Ongoing Gaps and Challenges
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Proposed Principles of Health Data Use

The principles outlined below refer to data about individuals related to their health and health care that are collected by diverse sources, including electronic health records and remote monitoring. The Meeting Steering Committee developed these principles for reference during the AMIA 2012 policy meeting.

1. Appropriate ongoing use of patient health data beyond clinical care of individuals is essential for the nation as a whole and for individuals in order to achieve better health, and safer, better quality of care. Health data should be available and usable on a continuous basis for various purposes.

2. In order to maximize their utility, health data must be made as trustworthy, timely, accurate, accessible, and reliable as possible, and we must be able to track the degree to which health data have attained these properties.

3. Different people, organizations, and stakeholders have varying perceptions and relationships with data that must be honored in order to achieve the compelling and mutual benefits of health data use.

4. There are growing and divergent needs for health data to address efficacy, safety, and effectiveness of health care. Examples include:

   • Data are needed to promote health improvement and maintenance; disease prevention; treatment targeting and improvement; and reduction of health care costs.
   • Data can help identify, track and address public and population health challenges as well as health issues related to environmental concerns and natural disasters.
   • Data can help improve the health and care of future patients who might have the same or similar conditions.
5. Safeguarding health data from inappropriate use or misuse is essential to assure public support and patient confidence. Those who maintain, aggregate, and use health data, must demonstrate that they are worthy of trust in order to earn and retain the support of patients and the public.

6. There is some risk, however small, of loss or disclosure of confidential patient data. Therefore, in any use of health data, the costs of such loss or disclosure as well as the potential benefits of data use must be carefully assessed.

7. It is not feasible to anticipate all future data sources or data capture technologies and techniques and their potential impact on using data to achieve better health and better quality of care. Thus, healthcare system stakeholders must continue to study the impact of use of health data on research and discovery of new knowledge, quality improvement, public health surveillance, and cost reduction, refining these principles as needed, and continually seeking to achieve an appropriate balance between privacy and security and data use.