Health data use, stewardship, and governance: ongoing gaps and challenges: a report from AMIA’s 2012 Health Policy Meeting

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Abstract

Large amounts of personal health data are being collected and made available through existing and emerging technological media and tools. While use of these data has significant potential to facilitate research, improve quality of care for individuals and populations, and reduce healthcare costs, many policy-related issues must be addressed before their full value can be realized. These include the need for widely agreed-on data stewardship principles and effective approaches to reduce or eliminate data silos and protect patient privacy. AMIA’s 2012 Health Policy Meeting brought together healthcare academics, policy makers, and system stakeholders (including representatives of patient groups) to consider these topics and formulate recommendations. A review of a set of Proposed Principles of Health Data Use led to a set of findings and recommendations, including the assertions that the use of health data should be viewed as a public good and that achieving the broad benefits of this use will require understanding and support from patients.

Background

A convergence of public policies, activities, trends and technological advances has resulted in the increased collection and availability of personal health data. Recent national efforts have incentivized the adoption and meaningful use of EHRs.6–9 Disease registries and other large-scale data sharing initiatives generated in the public and private sectors have proliferated along with efforts to integrate and analyze the data in them10–15 (see online supplement 1, chart 1, ‘Selected examples of data reuse and sharing projects and activities’, which was prepared for the 2012 Health Policy Meeting). New sources of data are being driven by emerging technologies (eg, streaming from mobile devices and implants, generated by sensors), including the integration of personal genomic data into clinical practice which looms on the horizon. While data use efforts are moving forward throughout the healthcare system, public policies related to stewardship and governance of the data have not kept pace with rapidly emerging technologies; questions are arising about the roles and responsibilities of patients and consumers with respect to their data; and concerns are being raised about whether the data are of sufficient quality for some proposed uses. Against the backdrop of increasing use of healthcare data, stakeholders (including patients) continue to seek the right balance between providing access to and use of health data and ensuring patient privacy.16–18

As noted above, there is widespread agreement on the value of personal health data for many uses beyond direct patient care and treatment. Thus, discussions about the appropriate stewardship and governance of the data are more important than ever. Rosenbaum defines data stewardship and data governance as follows: ‘Reflecting the values of fair information practice, data stewardship denotes an
approach to the management of data, particularly data that can identify individuals. The concept of a data steward is intended to convey a fiduciary (or trust) level of responsibility toward the data. Data governance is the process by which responsibilities of stewardship are conceptualized and carried out.19

Recent activity on the international scene and in the USA
In 2011, representatives of major global health funding agencies issued a joint statement outlining high level principles and goals that promote the wider sharing of data to achieve better public health worldwide, while at the same time acknowledging the need to ‘protect the privacy of individuals and the dignity of communities’.20 The 2012 European Summit on Trustworthy Reuse of Health Data concluded that health data reuse processes must be transparent, the patient must be fully informed, and national governments must play a pivotal role.21 Relevant reports in this arena include: from the UK, the NHS Confidentiality Code of Practice;22 the Caldicott Information Governance Review;23 and the Care Quality Commission’s Information Security and Governance Policy;24 from the European Union, the EU Data Protection Principles;25 and from New Zealand, Information Governance in the NZ Health Sector.26

In the USA, federal level, policy-related organizations have moved the national dialog about data stewardship forward in recent years. In a 2009 report, the National Committee on Vital and Health Statistics (NCVHS) noted that “The principles of data stewardship are now well established; the work of translating them into practice will continue to evolve as the urgency of data stewardship grows ever greater in the future.”27 The evolution of data stewardship efforts continued the next year with the HIT Policy Committee recommendation to the National Coordinator for Health IT (DHHS) that ‘fair information practices...constitute good data stewardship and form a foundation of public trust in the collection, access, use and disclosure of personal information’.28 The HIT Policy Committee followed up in 2011 with a recommendation that uses of EHR data ‘for treatment purposes or to evaluate the safety, quality and effectiveness of prevention and treatment activities should not require consent, IRB approval, or even minimal registration’.29 In 2012, acknowledging the many new ways that data are being used to address community health issues, the NCVHS again weighed in on the topic, offering a framework and principles for effective community health data stewardship.30

Efforts related to data stewardship also progressed at the federal level via a final rule promulgated by DHHS in 2013 that enhanced Health Insurance Portability and Accountability Act (HIPAA) privacy, security, and enforcement regulations through the following changes: limiting the disclosure of information when patients pay by cash; setting new limits on how information is used and disclosed for marketing and fundraising; prohibiting the sale of an individual’s health information without their permission; strengthening enforcement of HIPAA privacy and security protections; and streamlining individuals’ ability to authorize use of health information for research.31 Ongoing federal-state healthcare coordination efforts, operated under DHHS contracts, aim to ensure that State and regional efforts to achieve health information exchange are aligned with the national health IT agenda.32

Experts explore data sharing policy challenges
The Institute of Medicine (IOM) convened a number of recent meetings focused on advancing the ‘continuously learning healthcare system’ that address the challenges and opportunities inherent in linking and sharing the growing amounts of available health data.33 34 In the comparative effectiveness research arena, Sittig and Hazelhurst35 included, among several ‘informatics grand challenges’, the necessity of developing new data governance models that would expedite analysis of data sets held by different institutions. AcademyHealth’s HealthIT for Actionable Knowledge project issued a 2012 paper exploring legal and policy challenges associated with reuse of electronic clinical data, including variable interpretation of federal laws governing these uses, challenges related to IRB review, and potential variability in relevant state laws.35

Involvement of patients in data use activities
Patient activation and engagement in healthcare has been referred to as the ‘blockbuster drug of the century’.36 As part of this engagement, patients in various clinical settings are accessing their health data electronically. An online survey conducted for the National Partnership for Women & Families in 2011 reported that 80% of Americans who are able to access the data in their EHRs use the information.37 Data from a Kaiser Permanente study, which looked at use of online health services that Kaiser provided via a patient portal, indicated that the number of visits to the portal tripled between the time that it was first deployed in 2004 (10.7 million visits) and 2007, when there were almost 33 million total visits; when online test results began to be offered, they became the most visited feature on the site.38 Further promoting this trend, in 2014, the DHHS rule for Meaningful Use Stage 2 will require healthcare providers using EHRs to enable more than 5% of patients to electronically view, download, and transmit their data (eg, lab test results, medication lists).39

Patients have begun demanding access to their data, including the medical data streaming from devices implanted in their bodies.40 41 Recent discussions in the USA and in other countries have focused on the benefits and challenges of making patient data available for research,42 with patients weighing in on their willingness to make their data available for purposes other than direct care.43 An IOM paper issued in 2012 reported on research that indicated that 89% of patients strongly agreed or somewhat agreed that their data ‘should be used to help improve the care of future patients who might have the same or similar condition’.44 The Patient-Centered Outcomes Research Institute (PCORI),45 funded by Congress as part of the Patient Protection and Affordable Care Act, engages patients as partners in the development of a patient-centered research community.

Patient-generated initiatives, such as PatientsLikeMe,46 are working to promote access to data, and to actively share the data to speed research collaboration on new treatments. In May 2013, the Health Data Exploration Project was launched by the California Institute for Telecommunications and Information Technology (Calit2), with support from the Robert Wood Johnson Foundation. This project is working with health researchers and technology and consumer electronics companies to explore approaches to broadening the use of new sources and forms of health data (eg, health data captured via smart phone apps). The project’s aims are to improve individual and population health as well as to overcome barriers to the use of these new health data.47 Attention is also focusing on involving patients in the collection of data in EHRs. For example, Estabrooks et al48 identified selected patient-reported data on health behaviors and psychosocial factors that could be included in the EHR to improve patient care.

While many researchers, clinicians, and patient advocates promote increased sharing of personal health data, concerns
continue to be raised about potential harm to patients from making health data more openly available. However, McGraw et al argue against viewing privacy concerns as an obstacle to the use of health IT in efforts to achieve the learning healthcare system. In order to build the necessary public trust in health IT, McGraw posits that ‘we need a comprehensive, second-generation privacy and security framework that sets clear rules for access to, use of, and disclosures of personal health information (PHI) for all entities engaged in e-health and that includes adequate oversight and accountability.’

**AMIA’S 2012 HEALTH POLICY MEETING**

Recognizing the vast potential of health data use beyond immediate clinical care, the 2012 AMIA Health Policy Meeting examined the gaps and challenges that need to be overcome before this potential can be fully attained. The goals of the meeting were as follows:

- To further a national understanding of health data use.
- To review principles of data use that can be used to promote an appropriate, effective, informative, and balanced message about the value of health data use.
- To develop an action agenda about how appropriate health data use practices can best be supported by health IT and informatics, including next steps or areas for future research, strategies for implementation, and key policy issues.
- To formulate specific recommendations to government, industry, academia, and other stakeholders.

**Box 1  Proposed principles of health data use**

**Rationale**

A broad spectrum of health data is being collected and potentially made accessible via electronic health records (EHRs) and other repositories. From a clinical perspective, these data are used to inform decisions about individual patient health and wellness. Use of these health data beyond direct clinical care of individuals from whom the data were collected is essential to enhance healthcare experiences for individuals, improve healthcare quality and outcomes for individuals and population groups, and reduce system-wide healthcare costs. While access to and use of health data hold great promise to transform the healthcare system, public policy and technical challenges must be met before this promise can be fully realized.

Building on work conducted by participants at the 2007 AMIA Health Policy Meeting, the high level principles (presented below) were developed as a work product of AMIA’s 2012 Health Policy Meeting. Rather than serving as a blueprint for implementation of specific policies or regulations, they are intended as a guide to help healthcare system stakeholders (eg, data recorders, data users and re-users, policy makers and regulators) address key issues encountered in the move towards use of health data for the purposes noted above.

**Principles**

1. Access to and use of health data should be viewed as a public good. Data should be available and ‘fit-for-use’, with proper security, for appropriate purposes beyond direct patient care.
2. Health data must be as consistent, comparable, timely, accurate, accessible, complete, and reliable as possible. Users must be able to track the degree to which the data have attained these attributes. Understanding the context and provenance of the data is also critical in determining their ‘fitness for use’.
3. Integration and sharing of health data that currently reside in silos are necessary for the optimal use of the data.
4. The rights and responsibilities of everyone (including patients, families, providers, researchers, payers, and organizations) involved in collecting and using health data must be understood and respected.
5. Data uses must be transparent to all, including patients and their agents.
6. The potential benefits of data use must be weighed against the potential risks and costs of loss or inappropriate disclosure of personal health information.
7. Data stewards (those who collect, maintain, aggregate, analyze, and use health data) must demonstrate that they understand and are willing to assume the responsibilities of effective stewardship in order to earn and retain the support of patients and the public. Data stewards must demonstrate that they use data appropriately and in accordance with applicable laws and regulations.
8. Data use policies should not be so binding that they restrict or prevent uses of data from emerging technologies or impede as yet unknown data sources or technologies.
9. All healthcare system stakeholders must continue to study the benefits and risks of new data sources and uses and to refine data use principles as needed.

The meeting convened on December 12–13 in Washington DC. Prior to the meeting, a Steering Committee, chaired by George Hripcsak, Chair, Department of Biomedical Informatics, Columbia University, and made up of AMIA members who are experts in the field, determined the meeting goals, set the agenda, and suggested presenters and attendees. The Committee also developed a draft set of principles; these principles, incorporating comments by meeting participants, are presented in box 1. The nearly 100 attendees included representatives of various stakeholder groups: providers, informaticians, technology vendors, specialty societies, pharmaceutical companies, consulting firms, researchers, and government agencies. This meeting also benefited significantly from the presence and active participation of several representatives of patient and consumer groups, who provided valuable insights into data use and privacy issues.

Several plenary sessions featured speakers who addressed various aspects of the data use topic:

- Christopher Chute, Professor of Medical Informatics at Mayo Clinic College of Medicine, provided an update on the ONC Secondary Use SHARP Grant.
- Charlie Safran, Chief of the Division of Clinical Computing, Beth Israel Deaconess Medical Center and Harvard Medical School, reported on the EU Data Stewardship Framework.
- Gurvaneet Randhawa, Agency for Healthcare Research & Quality (AHRQ) Medical Officer, offered an overview of relevant AHRQ activities.
Don Detmer, Professor of Medical Education, Department of Public Health Sciences, University of Virginia; Patti Brennan, national program director of Project Health Design (and co-chair of the AMIA Health Policy Meeting); and Soumitra Sengupta, Chief Information Security Officer, New York-Presbyterian Hospital and Columbia University Medical Center, participated in a panel on potential reforms of national policies supporting secure access to personal data for research.

Peter Embi, Associate Professor of Biomedical Informatics and Internal Medicine, The Ohio State University, identified impediments and future challenges to data use.

Jane Thorpe, Associate Research Professor, School of Public Health and Health Services, George Washington University, reviewed considerations for data stewardship and governance.

Facilitated breakout sessions were the heart of the meeting, during which participants discussed a broad variety of approaches to meeting the challenges outlined in the conference’s goals. Participants worked in small groups to articulate the value of data use for various purposes, and identified major future challenges, gaps, and barriers to appropriate and effective health data use. Looking toward the future, they recommended actions in the policy, regulatory, research, and technological domains (see ‘Findings and recommendations’ below).

### Terminology

In a 1998 paper, Chute et al discussed the importance of developing and employing a common terminology to help meet key challenges posed by healthcare’s computerized clinical data and associated uses. One of the important discussion topics at the 2012 meeting was clarification of terminology related to ‘secondary use of data’. In the paper outlining the results of AMIA’s 2006 Health Policy Meeting which discussed creation of a national framework for secondary use of health data, secondary data use was defined as ‘non-direct care use of personal health information (PHI) including but not limited to analysis, research, quality and safety measurement, public health, payment, provider certification or accreditation, and marketing and other business including strictly commercial activities’. In 2007, the NCVHS recommended dropping the term ‘secondary use’, noting that it was used inconsistently to refer to different types of data use and implied that some uses are less important than others. Currently, the term ‘reuse’ is being employed by many stakeholders to express the concept of using health data for a purpose different than the one for which it was originally collected.

Contributing to the ongoing discussion about terminology, participants at the AMIA meeting put forward the concept of ‘continuous use’ of data: ‘To the extent possible, data should be collected once and used continuously. Ensuring data quality and certainty, data collectors, data stewards, and data aggregators must help assure that data are available continuously for appropriate querying and uses.’

### FINDINGS AND RECOMMENDATIONS

The discussions about data stewardship and its challenges, conducted at AMIA’s Health Policy Meeting, took place within the overall context of national efforts to achieve widely recognized goals of improving healthcare quality and outcomes for individuals and population groups, and reducing system-wide healthcare costs. While various federal and state agencies—as well as numerous private sector organizations—are working toward realization of these goals, strategies are often poorly coordinated and crucial research and policy development work is not being undertaken. The main purpose of the meeting, as reflected in the findings below, was to address key challenges in the areas of health data access, use, and governance. This focus did not include the related topics of data quality and data standards, which, while clearly critical to effective data use, fell largely outside the purview of the meeting.

1. **Finding.** Crafting public policies to facilitate the appropriate use of health data to improve the quality, efficiency, safety, and patient-centeredness of healthcare must be elevated to a national priority and integrated within related national and state strategic initiatives. The goal should be development of a coordinated health data use strategy and action plan.

   **Recommendation.** A major public–private sector effort should be undertaken to develop and implement a national health data use strategy, beginning with a focused national dialog among diverse stakeholders and the public and resulting in a coordinated action plan.

   The underlying premise of this dialog should be that there is substantial value to stakeholders of appropriate health data use beyond direct patient care. Inherent in this dialog should be a focus on understanding the risks of such data use and how to mitigate them. A coordinated strategy and action plan should address intellectual property, ethical, proprietary, and commercial issues such as organizations’ reluctance to share data, and concerns around sale of data. It should also tackle emerging public policy complexities in the area of data use arising from widespread adoption of technology-based advances such as EHRs, exchange of data via the cloud, and data becoming available from beyond the point of care (eg, mobile devices, biomedical sensors, genomic data, social media). Strategies should include acceleration of efforts to harmonize existing Federal regulations and contemplated revisions (eg, the Common Rule, HIPAA). A collaborative effort by healthcare stakeholders (including patients and consumer groups) to advance the dialog and to develop an action plan is critical. (See Finding 5).

   **Recommendation.** The national strategy and action plan should promote the appropriate sharing of health data throughout the global healthcare community, and develop methods to resolve the attendant issues. Productive activities in these areas are already underway in Europe and elsewhere, and these efforts should be accelerated and harmonized with related US activities. The DHHS should monitor and participate in national and global activities such as the Transatlantic eHealth and Health IT Cooperation Roadmap. In addition, US developers of principles and best practices should consult relevant work done outside the USA, as noted above.

   **Recommendation.** Federal, state, and local agencies as well as private sector groups should work together to examine and harmonize existing and contemplated data use policies at the federal, state, and local community levels (eg, policies related to data in HIEs) (see online supplement 1, chart 2, ‘Selected examples of federal government agency/organization data sharing and re-use activities and policies’, which was prepared for the 2012 Health Policy Meeting).

2. **Finding.** Data stewardship and governance principles and policies need to be articulated that meet the challenges posed by technology-enabled sources of health data and the increased emphasis on patient-centered healthcare. These policies and principles need to be disseminated and implemented via data stewardship models and best practices.

   **Recommendation.** Policies are needed for gaining access to and promoting use of the very large data repositories being generated outside of typical clinical settings. Multidisciplinary teams (including consumers and patients) should determine
what changes are needed in public policies and regulatory processes as they relate to provider responsibility and patient privacy for these new types of data.

Recommendation. Work that is underway by the DHHS Health IT Policy Committee Governance Workgroup to prepare recommendations on governance of nationwide health information exchange should take into consideration emerging data uses as well as current ones. Multiple-system demonstrations of governance models should be accelerated, with the aim of developing widely-accepted best practices of appropriate data use, including processes that provide for patient participation. Efforts in this arena should leverage the work undertaken by state health information exchanges, projects funded by AHRQ such as the PROSPECT studies, and the Electronic Data Methods (EDM) Forum for Comparative Effectiveness Research; the ONC Beacon communities and SHARP grantees; National Institutes of Health (NIH) Clinical and Translational Science Awardees; stakeholder organizations such as the American Health Information Management Association (AHIMA) and ARMA International; and groups working to promote patient-centered care such as PCORI.

3. Finding. Enforceable data stewardship guidelines are needed to assure all healthcare system stakeholders that data is safeguarded according to accepted standards and best practices. Such guidelines and standards could be included in any enhanced future HIPAA policies.

Recommendation. The DHHS should coordinate and implement a multi-stakeholder effort to develop, endorse, and deploy a certification process and training program that promotes best practices in data stewardship and identifies criteria for ‘certification’ of data stewards who are entitled to be viewed as trusted parties. (See ARMA International’s description of certification for an information governance professional.)

Recommendation. Additional study is needed to understand the degree to which data de-identification techniques are protective of data and reduce the potential for re-identification. Public and private sector funding is needed so that researchers can further develop and test effective approaches to de-identification of data that mitigate re-identification consequences. Best practices and lessons for data de-identification should be established and widely disseminated.

4. Finding. Further study and coordinated efforts are needed to improve current consent and privacy practices to assure more transparency in health data use (eg, in research); promote patients’ understanding and acceptance of the practices; and facilitate implementation of these complex processes. Given the increased engagement in healthcare decision making by patients and consumers, it is critical that representatives of these groups be partners in these explorations.

Recommendation. The public and private sector should fund additional efforts to address key questions related to consent and privacy practices, including the following: What type(s) of consent or waiver of consent are required for research and at what points in the research is the consent or waiver required? What would be the impact on research of including only data from individuals who have given consent? What are the benefits and drawbacks of opt in versus opt out methods? Is consent required for use of de-identified data or should it be waived? What consent methods are appropriate for genomic data? What level of consent granularity is needed for different purposes?

Recommendation. DHHS should convene a broad-based working group of public–private sector stakeholders to identify the minimum elements needed in consent documents; develop consent-related standards including clarification and standardization of terminology and vocabulary around consent; and create and test best practices models and templates for key consent situations. Throughout these efforts, attention must be paid to the critical importance of using plain language in consent materials and to addressing challenges raised by translations of the materials into languages other than English.

Recommendation. DHHS should accelerate research on and widely disseminate findings from ongoing research to explore new, improved methods of delivering and obtaining consent.

Recommendation. DHHS and other stakeholders need to further compile and disseminate information about current state policies, regulations, and laws with respect to patient consent and privacy, with an eye toward development of model state policies that can promote harmonization.

5. Finding. In order for use of health data to achieve its promise, it is necessary to gain support from consumers and patients regarding use of their data.

Recommendation. Public and private sector funding is needed to support additional research to better understand consumer views on use of health data. Examples include ethical and social reactions to the use of health data for research and the effect (if any) of social media use on how people view health data privacy issues.

Recommendation. Based on the results of the research, a public campaign should be developed which highlights the tangible value and potential ramifications to consumers of health data use. All aspects of the campaign should be developed in collaboration with patient and consumer groups (eg, PatientsLikeMe, National Organization of Rare Diseases, Genetic Alliance, Center for Democracy and Technology) that can tailor and present the campaign to their constituencies in their publications, meetings, etc. The campaign should employ mechanisms such as infographics that use graphics to visually represent information. Campaign work should build on and be coordinated with existing programs such as CMS’s Partnership for Patients, and the ONC Consumer e-Health Program.

Recommendation. DHHS and other federal entities need to implement and widely publicize easy-to-use mechanisms to assist individuals who are interested in donating their data for various purposes. Some initial ideas include an incentive program for research-ready consumers and a Green Button program, similar to the Blue Button program, to encourage the public and patients to Be a Data Donor.

Recommendation. Public and private stakeholders need to further develop and implement programs to promote health literacy among consumers, patients, and their families so that they can better understand the advantages of health data use as well as the challenges and risks.

6. Finding. In order to obtain maximum value from the use of health data, the healthcare system will need to make significant investments in workforce development and training. While numerous technical skills and proficiencies will be needed, all data users should thoroughly understand and apply data stewardship practices as appropriate to their role within an organization.

Recommendation. Clinical (medical and nursing), allied health, and public health education programs should train students about the value of health data use, methods of integrating data into their daily work, and data stewardship principles and best practices. Curricula should be updated to reflect appropriate use of health data as part of integrated, team-based care delivery and research.

Recommendation. Professional groups, medical educators, and consumers should work together to determine the skill sets that are needed for active participation in a health learning
system in which use of health data is the norm. These skill areas include clinical and health services research, informatics, statistics, computer science and engineering, data stewardship, medical ethics and counseling, social media use, and plain language. As these skill sets are further defined, it will be necessary to articulate specific competencies and develop training and continuing education programs using traditional and non-traditional media. Examples of training models that provide a grounding in data stewardship include ARMA International’s Information Governance Professional Certification and AMIA’s Clinical Informatics Board Review Course, aimed at assisting board-certified physicians to become certified in the subspecialty of clinical informatics.

CONCLUSIONS

With the overarching goal of furthering a national understanding of health data use in the context of a dynamic technological and social environment, AMIA’s 2012 Health Policy Meeting identified challenges to health data reuse, and articulated several conclusions:

- The development of a coordinated health data use strategy and action plan should be a national priority, including the integration of public policies for health data use into health-care system strategic initiatives.
- There is a clear and pressing need for data stewardship and governance guidelines and best practices that can be applied by all data providers and users.
- Data stewardship policies should be enforceable.
- Approaches to informed consent need to be revised to improve usability and take advantage of new technologies, and these efforts must engage patients as partners.
- Broad public support from patients regarding use of their data is needed for the promise of health data use to come to fruition.
- Investments in workforce training are needed to ensure that all data users understand and apply data stewardship principles.

These conclusions, as well as the Proposed Principles of Health Data Use developed at the meeting, fully recognize the need to strike a balance between the protection of patient privacy and the benefits that shared data use offer to improve healthcare outcomes and reduce costs.

AMIA BOARD OF DIRECTORS’ RESPONSE AND ACTION

By convening this meeting and disseminating this report, AMIA has identified health data use, stewardship, and governance as ongoing and critical issues for the continued widespread adoption of health information technology. The AMIA Board of Directors reviewed the paper and endorsed the authors’ recommendations. The Board anticipates committing additional organizational resources to continue to advance the work of the meeting and will encourage other organizations to work collaboratively to pursue the recommendations and to continue this important public discourse.

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