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Whose Data is it Anyway?

Expanding Consumer Control over Personal Health Information

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After a comprehensive review and analysis of the legal and technical landscape around the rapidly evolving terrain of personal health information, Manatt Health Solutions recently authored a pioneering policy issue brief on behalf of the California HealthCare Foundation, an independent philanthropy based in Oakland, California that is committed to improving health care delivery and financing systems.

Mounting evidence indicates the importance of engaging patients directly in their care. Yet in today's health care environment, consumers typically must gather and store personal health information on paper and from multiple providers which is time-consuming and burdensome. The information often is fragmented and incomplete, and transmitting it to other providers is onerous for consumers and providers alike.

Introduction

Health information in the United States is largely possessed and controlled by clinicians who provide care and by insurance companies and other entities who pay for care. While federal and state laws give consumers the right to obtain paper copies of their medical records, the terms of such transactions may be too costly or too time intensive, resulting in suboptimal patient care. Moreover, the information cannot be readily transmitted and, for both patients and providers of care, generally is not useful in care delivery, outcomes analysis, or biosurveillance.

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An increasingly antiquated legal structure is significantly shaping the technological, operational, and business models that are evolving for the custodianship of personal health information. Consumers now expect to be able to access various types of information on the Internet. With the rising adoption of health information technology and the increasing ability to collect, store and exchange information electronically, a growing number of consumers also expect to be able to access their personal health data on the Internet. In an ideal, electronically enabled health care system, consumers could easily transmit discrete portions or comprehensive files of their data to the caregiver(s) of their choice for direct care or other purposes, on demand and in a matter of seconds. They could access their personal information from various sources, store it in one location, and automatically receive updates—including notification of such—from these sources. And they could organize the information in formats that are meaningful to them and their health care providers, and take advantage of features that educate them and help them participate in their care.

As health care transitions from paper-based to electronic records, there is a significant opportunity to expand the traditional concept of consumers' rights to access and use their personal health information. Such access and use are crucial prerequisites to realizing the full potential of technologically driven advances in the health care system. The potential role of personal health information custodians, or third parties, in helping consumers obtain, organize, and use information to improve their health is gaining recognition. This policy brief explores important issues that must be addressed if consumers are to have meaningful rights to access, use, and control their electronic health information through a personal health information custodian serving on their behalf.

Key Findings of the Policy Brief

- Redefining consumers' rights will require a fundamental shift from the current legal structure, in which clinicians control medical records and determine the permissible circumstances for disclosing the information in them, to a new legal structure in which consumers have affirmative right to access electronic information regardless of its source and to use it as they deem necessary.

- New laws could give consumers the right to direct that a copy of any personal health information stored in a

standardized electronic format be sent to the custodian of their choice, and ensure that the custodian uses the information in a manner specified by the consumer.

- Current regulation of personal health information under federal and state law is fragmented. Because federal law does not preempt more stringent state privacy laws, and because Congress has not chosen to act, states may have to take the near-term reform initiative.
- New laws will require a clear definition of “personal health information custodian.” They should also include safeguards under consumer protection laws to ensure that such information remains secure and is not used inappropriately, affirm the right of consumers to send and store the information as they see fit, and set fees for electronic transmissions of medical data from providers to patients.
- Economic incentives for clinicians to adopt a technology enabling them to convey personal health information to patients would facilitate the transition to a new legal framework. Eventually this capability might be required as a condition for receiving federal reimbursement under Medicaid, Medicare, or other government-financed programs.

Conclusions

As adoption of health information technology and the ability to exchange personal health information advance, so too should the legal foundation that facilitates access to and control of such information for consumers’ benefit. Early technological advances offer a window of opportunity to design legal parameters for appropriate consumer access and control, regardless of the information’s source or how it is used.

At a minimum, new laws should give consumers an affirmative right to authorize the transmission of any standardized, electronic personal health information to a custodian of their choice, and ensure that custodians use that information in a manner directed by consumers. These laws would have significant potential to engage patients in their health care by clearly defining their rights (thus winning their trust) and fostering models of information custodianship that support their needs.

A full copy of the brief may be downloaded at the California HealthCare Foundation’s website (www.chcf.org).

Manatt’s Health Information Technology and Policy

Experience

Manatt Health Solutions professionals possess comprehensive knowledge of the health IT environment from a public policy and private sector perspective. Our extensive experience developing and implementing health IT initiatives on a national, state, local, and provider-specific level uniquely qualifies us to provide creative and practical approaches to the opportunities and challenges that arise in enabling health IT. For more information about personal health record activities at the national, state or local level and Manatt Health Solutions' legal, advocacy, or business advisory capabilities, please contact William Bernstein (212-830-7282) or Julie Murchinson (415-291-7440).

[back to top](#)

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Julie V. Murchinson Ms. Murchinson is a Managing Director of Manatt Health Solutions, a policy and strategic advisory division of Manatt, Phelps & Phillips, LLP. Ms. Murchinson has over fifteen years of experience in the healthcare industry. She has a strong background in assisting healthcare organizations with business strategy, operational design, service operations and change management for information technology use. Ms. Murchinson's unique approach addresses the impact of information technology on all aspects of an organization and business model.



Melinda J. Dutton Ms. Dutton serves as a Partner within the healthcare division of Manatt, Phelps & Phillips, LLP (Manatt), and also plays a leadership role within Manatt Health Solutions (MHS), the Firm's interdisciplinary policy and business advisory practice. Ms. Dutton's practice concentrates on advising clients in the healthcare industry with respect to strategic, business, public policy and regulatory matters. Ms. Dutton's clients include hospitals, community health centers,

long-term care providers, foundations, government agencies, health information exchange initiatives, industry associations and consumer advocacy organizations.



Terri D. Keville Ms. Keville is recognized for her expertise in healthcare litigation and healthcare facility operations, particularly medical staff matters. Her litigation practice focuses on case-dispositive motions and appeals (including participation as amicus curiae) in civil litigation involving hospitals and hospital systems, nursing homes, physician groups, and other healthcare providers, plans, and trade associations. Ms. Keville has made new law for California healthcare organizations in cases involving physician peer review, Medicare preemption, ERISA preemption, and California's Unfair Competition Law.



Robert D. Belfort Mr. Belfort has broad experience in the representation of healthcare organizations on regulatory and transactional matters. His clients include hospitals, community health centers, mental health providers, insurers, managed care plans, pharmaceutical manufacturers, pharmacy benefit managers, disease management companies, nursing homes and a variety of other businesses in the healthcare industry. He has also worked extensively with provider and health plan trade associations.

[back to top](#)