Patients as first-order participants in health, health care, and research

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Access to information and the ability to integrate and use information has changed how individuals book travel, find information about prices and products, and compare and review services. Information can empower individuals, but health care has lagged behind other fields.

But that is starting to change, and the American Medical Informatics Association (AMIA) can be the advocate for patients to be first-order participants in their health, health care, and in research across the entire learning health system. With our diverse membership, AMIA is uniquely positioned to be an advocate for using information in service to consumers and patients.

Within the informatics research community, at least two key research initiatives highlight the change in how patients can interact with research. The Patient Centered Outcomes Research Institute (PCORI) and PCORnet have made patient engagement a priority in outcomes research. Within PCORnet, there are 18 Patient-powered Research Networks that have substantial roles for patients in recruitment, governance, and establishing priorities. These networks encourage patients to securely share their own data from devices and from electronic medical records to accelerate clinical research. These networks involve patients in all aspects of research, including dissemination of the results.2

A second effort was announced by President Obama in January 2015. The Precision Medicine Initiative aims to recruit 1 million individuals to participate in a longitudinal study3,4 and use that patient-specific information to precisely target interventions for individuals. AMIA members were key participants in the first workshop linking patient data in electronic health records to the research community5 and recognized the importance of patients being able to use their own data to participate in these studies.

For these efforts to be successful, however, we need patients to be empowered not only to participate in research activities, but also to have full and unfettered access to electronic information stored in electronic medical records. While good progress has been made with the meaningful use program to support patients’ access to their summary record and patient portals, this is not sufficient for patients to participate in research or in their medical care. It is unconscionable that in 2015 most patients are unable to obtain their entire medical record unless they print it out. If the information is stored electronically, patients should be entitled to their entire medical record in an electronic format and not just a summary record or the limited data that a vendor chooses to make available. With access to their own information, patients can use that information as they see fit—to support research and causes that they believe in.

If we fail to engage patients in clinical research, they will move on without us. More substantial changes are likely to come in how individuals interact with health information—information from home monitoring devices, from FitBits (Fitbit Inc, San Francisco, California), Apple Watches (Apple Inc, Cupertino, California), Microsoft Bands (Microsoft Corporation, Redmond, Washington), or other personal devices. The data from these devices soon will eclipse the volume of data that is in the health care system, and it will be patients—not researchers or medical providers—who will have this data.

In the informatics community, we have an opportunity to advocate for patients to be first-order participants in clinical research, in their health care, and in their health. As has happened in other aspects of modern life, technology has empowered individuals in their interactions. We in the informatics community should not only embrace this change, but also accelerate it in the research and applied work that we do—from basic science research to the implementation of systems that engage individuals in their health and health care.

REFERENCES

The purpose of the Messages from AMIA section is to provide a forum for AMIA to inform and involve its current and potential members about the goals and the directions of the association. These messages, which reflect the directions and opinions of AMIA leaders only, are intended to inspire members and readers to connect with the association on strategic objectives and activities. See also http://www.amia.org/presidents-page.