

Case 100

Connecting for Health: A Public-Private Collaborative

John and Mary R. Markle Foundation, 2002

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Background. Since 1969, when Lloyd Morrisett assumed its presidency, the Markle Foundation has focused on “mass communications in a democratic society” as a means “to promote the advancement and diffusion of knowledge . . . and the general good of mankind.”¹³⁸³ In 1988, under the leadership of current president Zoë Baird, the Foundation narrowed its focus to “information and communication technology.” Today, this remains the lever by which Markle seeks to leverage its modest resources—about \$140 million in assets—to achieve sustainable impact in two program areas: Health and National Security.

In its Health program, the Foundation seeks to ensure that the enormous potential of information technology (IT) is realized in the health and health-care fields, and that the primary beneficiary of this realization is the patient.¹³⁸⁴ To that end, the Foundation in 2002 launched Connecting for Health: A Public-Private Collaborative. The initiative draws together all the relevant stakeholders in the field, including physicians, hospitals, patients’ advocates, IT professionals, and government, in an effort to guide the spread of IT into healthcare.¹³⁸⁵ To understand the significance of this effort, it is necessary to consider how antiquated are most American health systems. In a field characterized by ever-shifting boundaries of possibility, enormous resources, and rapid technological advancement, paper records remain almost universal, and physicians often have little or no way of knowing their patients’ full medical histories. The system is reliant upon patient visits even for minor services: a dynamic that benefits healthcare providers, but inconveniences, and often overcharges, the mass of healthcare consumers.

Strategy. Through the Connecting for Health initiative, the Markle Foundation plays the role of a neutral, disinterested convener. It is a role that no other stakeholder in the system could play. In 2002, the Foundation committed \$2 million to the project, much of which has gone for research, small demonstration projects, and other ways of building the evidence base to encourage the development of personal, portable, electronic health records. Such records can improve the quality of care received by enabling a doctor to know exactly what the patient’s medical history is (allergies, possible drug interactions, tests already received etc.). They also offer the promise of increased security, as patients have both ownership of and access to their full medical histories. Personal electronic health records can enable patients not to be the passive consumers of healthcare they all too often are.

Still, the money spent by Markle has been primarily for the “glue” that binds together the project’s more significant efforts. The real meat of Connecting for Health is its steering committee and its working groups. The steering committee, now composed of over sixty members, includes an enormous range of stakeholders all working though their many differences toward shared goals—the improvement of health care provision, the increased accessibility of health care to all Americans, and the maintenance of high standards of privacy in medicine. The committee meets to develop standards for the use of IT in health care. Markle also convenes several working groups, which gather to research and make recommendations about thorny issues of IT development. The members of the steering committee and the working groups freely donate their time, and the Foundation’s calculations show that the value of time donated exceeds—by several orders of magnitude—the money spent on the initiative. Concerned that IT was developing ever more, and ever better discrete silos of information, where knowledge lived and died, the Markle Foundation convened this collaborative to promote the sharing of knowledge and the airing of concerns in the hope that the

benefits of IT could accrue to all—not just to those with market power. One major interest of the Foundation—openly espoused—has been *interoperability*, or open standards. In effect, the Foundation has sought to guide the steering committee’s discussions toward a realization that health records must be portable—and therefore transferable among systems (like e-mail)—or else the patient will be held hostage by his or her current health plan or provider. Recognizing the potential of Connecting for Health, the Robert Wood Johnson Foundation in 2004 joined Markle as a funding partner. To date, the two foundations have spent a total of approximately \$3 million on the project.¹³⁸⁶

Outcomes. The outcomes achieved by the collaborative have been impressive. In March 2003, Secretary Thompson, of the U.S. Department of Health and Human Services, announced that the Connecting for Health standards would be adopted by the federal government as it moved toward the goal of personal electronic health records.¹³⁸⁷ In his announcement, Secretary Thompson explicitly thanked the Markle Foundation for enabling the conversation about IT in healthcare to take place at all, and to include such a wide range of stakeholders. This inclusive approach, which rejected no one who wanted to participate, made it easy for the federal government to accept the Connecting for Health standards without fear of some special-interest backlash. All the special interests had already been at the table negotiating. Such dissimilar leaders as President Bush and Sen. Hillary Clinton have both embraced the idea of portable personal electronic health records for all Americans.¹³⁸⁸ Dr. David Brailer, the federal government’s national health information technology coordinator was, until his appointment by President Bush, the chair of a Connecting for Health working group.¹³⁸⁹

Impact. The value added by Markle’s participation has been widely recognized. As a private foundation, Markle was able to fill a key niche: that of the convener. No other entity, public or private, would have been able to conduct the discussions that led to the Connecting for Health standards. A recent article, in the online version of the journal *Health Affairs*, estimates “that \$78 billion a year could be saved by moving to electronic patient records in a network with open communications standards, or interoperability, in computing terms.”¹³⁹⁰ To be sure, plenty of roadblocks remain. Privacy issues continue to be contentious, and the costs of maintaining electronic health records—about \$25,000 per year—remain prohibitive for many doctors’ offices. Market penetration is still only about 5 percent.¹³⁹¹ But the promise of IT for healthcare is now well understood. And patient welfare is now the guiding light for future progress. Before the Markle Foundation got involved, the conversation was barely taking place. Now, it is being conducted among all the relevant actors, and has won approval from key leaders in the private and public sectors. The Foundation secured a place for open standards and convened a discussion that continues to work through technical and financial roadblocks in the American healthcare field.

Notes

1383. The latter phrase is part of the mission statement of the Markle Foundation, which was founded in 1927 by John and Mary Markle, <http://www.markle.org>.

1384. *Ibid.*

1385. Carol Diamond, Managing Director of the Markle Foundation’s Health Program, Presentation to the Duke University Foundation Impact Research Group (FIRG); 1/19/2005. The presentation, for which the author was present, informs this case study throughout.

1386. Diamond, FIRG presentation, 1/19/2005.

1387. “Federal Government Announces First Federal eGOV Health Information Exchange Standards,” Press Release, United States Department of Health and Human Services, 3/21/2003.

1388. Diamond, FIRG presentation, 1/19/2005.

1389. *Ibid.*

1390. Steve Lohr, “Road Map to a Digital System of Health Records,” *New York Times*, 1/19/2005.

1391. Diamond, FIRG presentation, 1/19/2005.