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## NOTE

# THE EMERGENCE OF THE HEALTHCARE INFORMATION TRUST

*Paul T. Kostyack*<sup>†</sup>

### INTRODUCTION

**INFORMATION HAS BEEN SAID TO BE** the currency of the modern technological age. 'Our economy is not simply supplied by information, it is fueled by information.'<sup>1</sup> Today, information has become a secondary product of almost all transactions.<sup>2</sup> In fact, massive markets for secondary information are developing.

Today a company exists that gathers, consolidates, sorts, and reports information about nearly everyone in the country.<sup>3</sup> Axiom Corporation has information concerning over 196 million Americans.<sup>4</sup> The organization synthesizes information from a variety of sources including credit card transactions, real es-

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<sup>1</sup> Robert O'Harrow Jr., *Data Firms Getting Too Personal*, WASH. POST, Mar. 8, 1998 at A1 (quoting D. Van Skilling, CEO of Experian, a data-clearinghouse/credit reporting industry giant).

<sup>2</sup> See Richard S. Murphy, *Property Rights in Personal Information: An Economic Defense of Privacy*, 84 GEO. L.J. 2381, 2402 (1996) (discussing the information that is routinely disclosed in voluntary commercial transactions).

<sup>3</sup> See Nina Bernstein, *Lives on File: Privacy Devalued in Information Economy*, N.Y. TIMES, June 12, 1997, at A1.

<sup>4</sup> O'Harrow Jr., *supra* note 1.

tate records,<sup>5</sup> and 800-number telephone calls<sup>6</sup> for resale to corporations seeking to market to targeted demographics of consumers. The company's sales clearly demonstrate the growing financial relevance of the market in "secondary data";<sup>7</sup> Acxiom's revenues have increased a staggering amount in seven years from \$91 million in 1992<sup>8</sup> to nearly \$730 million in 1999.<sup>9</sup> Market observers suggest that enterprises will spend over \$10 billion dollars in 2000 in building and maintaining "data warehouses" of secondary information.<sup>10</sup>

The health care market is not without analogous, though more limited, initiatives. As an example, the Medical Information Bureau (MIB) has long compiled information on individuals for risk assessment and fraud avoidance by the insurance industry. As this Note will discuss, hospitals, health systems, and managed care health plans are becoming the central players to utilize the medical information collected on consumers in the growing secondary information market and to increase the value of health care data as a critical strategic resource.<sup>11</sup>

Health care, however, is an industry holding uniquely sensitive personal information, and its evolution may chart a different course than the secondary information markets evolving in other industries due to recently finalized federal health care information privacy rules.<sup>12</sup> Privacy advocates, due to the strong

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<sup>5</sup> *Id.*

<sup>6</sup> See Robert O'Harrow Jr., *A Hidden Toll on Free Calls: Lost Privacy*, WASH. POST, Dec. 19, 1999, at A1 (discussing the lack of prohibitions on the collection of telephone information).

<sup>7</sup> "Secondary data" in "secondary data markets" is, for the purposes of this Note, information collected at a primary consumer transaction (e.g., a doctor visit), which might be used for a purpose not relating to the primary consumer transaction (e.g., marketing pharmaceutical products).

<sup>8</sup> See ACXIOM, INC., 1992 ANNUAL REPORT.

<sup>9</sup> See ACXIOM, INC., 1999 ANNUAL REPORT 29, available at <http://www.acxiom.com/subimages/20042001AnRpt-99-FULL.pdf>.

<sup>10</sup> O'Harrow Jr., *supra* note 1.

<sup>11</sup> See Mariella Savidge, *Who's Selling Your Medical Information*, THE MORNING CALL (ALLENTOWN), Nov. 7, 1999, at D1 (discussing how the Medical Information Bureau Inc. collects medical information and sells it to insurance companies); Ray Reed, *Organization Compiles Medical Info*, ROANOKE TIMES, Jun. 9, 1998, at C1 (same); see also Paul M. Schwartz, *Privacy and the Economics of Personal Health Care Information*, 76 Tex. L. Rev. 1, 12 (1997) (noting that "[t]he practice of medicine increasingly depends on the large-scale comparison and analysis of personal medical information. As a result, health care institutions view personal medical information as a critical strategic resource").

countervailing value of medical information confidentiality, have convinced the federal government to adopt a form of "default privacy rules"<sup>13</sup> whereby explicit written "authorizations" will be required for health care providers, health plans, and data clearinghouses to use gathered medical information from health care purchasers for purposes other than care provision, claims payment, regulatory reporting, and research.<sup>14</sup> These regulatory initiatives will frustrate the emergence of a fully dynamic secondary market in medical information. They might, however, provide individuals with the ability to benefit from value inherent in the use of secondary health care data through a new organization, the Healthcare Information Trust.

This Note presents the concept of the Healthcare Information Trust and the reasons why it may be a preferable alternative to other organizations in managing secondary health care information. The Healthcare Information Trust is an organization with the fiduciary obligation to manage an individual's secondary health care information for the advantage of the individual as beneficiary. The Healthcare Information Trust may be the only organization that could maximize the value of secondary health care information to the individual and to a developing secondary health care information market.

This Note is divided into four parts. The first three parts lay the practical and legal groundwork for the emergence of the Healthcare Information Trust. In part one, the emergence of "integrated delivery systems" and "managed care organizations" as the developing focal points of health care information consolidation is discussed. The second part presents a simplified framework useful in understanding the nature of the threats and

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<sup>12</sup> See Standards for Privacy of Individually Identifiable Health Information, 45 C.F.R. § 164 (2000).

<sup>13</sup> See Schwartz, *supra* note 11, at 54-58 (discussing theoretical distinction between default and mandatory rules for information disclosure or privacy); see also Murphy, *supra* note 2, at 2383 (posing "the fundamental question [as] whether a rule permitting subsequent disclosure is superior, as a default rule, to a rule requiring privacy"); Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451, 521-26 (1995) (discussing concept of individual default ownership and control of the full longitudinal medical record used for any secondary purpose with non-informed consent use exceptions only in limited instances by health information "trustees").

<sup>14</sup> See 45 C.F.R. § 164.508 (regulating authorization for use of health information for secondary purposes by a covered entity).

opportunities inherent in the secondary use of health care information. This section also explores the economics of health care information, raising the possible implications of "default privacy rules" on the emergence of a dynamic "secondary health care information" market. The third part discusses the agency and market barriers to individual managed care organizations or integrated delivery systems, or their collaborative industry groups, emerging as the organizers of an individual's "longitudinal medical record." Finally, part four describes the conception of the Healthcare Information Trust as the organizer of the "longitudinal medical record," its promises and the major barriers to its possible creation.

### PART I: TECHNOLOGY, MCOs, AND IDSs

The health care industry is, arguably, on the cusp of technological capacity to realize the Healthcare Information Trust envisioned in this Note. Wide-scale consolidation and integration of information is occurring in the health care industry; these advances are occurring prominently in evolving "integrated delivery systems" and "managed care organizations."<sup>15</sup> These efforts, coupled with the increasing consolidation of the integrated delivery systems and managed care organizations within individual health care markets, may become viable primary sources of regional health care data repositories.<sup>16</sup>

Further, the Internet has become a ubiquitous technology that will emerge as the vehicle for disseminating the "longitudinal medical records"<sup>17</sup> providing new value to patients and pro-

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<sup>15</sup> This Note uses a number of acronyms for health care terms. A definition of "integrated delivery systems" or "IDSs" as used in this Note can be found, *infra*, at Part I.A. A definition of "managed care organizations" or "MCOs" as used in this Note can be found, *infra*, at Part I.A.

<sup>16</sup> A definition and discussion of "clinical data repositories" or "CDRs" and related "data warehouses" or "warehouses" begins, *infra*, at Part I.B.

<sup>17</sup> A longitudinal medical record is the health care record of an individual containing all medical and transactional data concerning an individual across all episodes of care and across all health care providers, insurers or administrators, governmental agencies or other individuals or entities maintaining health care information identifiable to the individual concerned. At present, of course, such a concept is theoretical, or an aspiration, since no such wide-scale comprehensive record system exists today. See Gostin, *supra* note 13, at 458 (calling it a "patient-based longitudinal health record"); see also INST. OF MED., NAT'L ACAD. OF SCIENCES, HEALTH DATA IN THE INFORMATION AGE: USE, DISCLOSURE, AND PRIVACY 5 (1994) (discussing comprehensiveness and inclusiveness of databases); Schwartz, *supra* note 11, at 52 (describing 'longitudinal oriented lifetime patient summaries').

viders. In other words, the Internet will soon become the backbone of longitudinal medical records, at least initially in read-only form, for individuals, providers and other health care information users. It will do this by providing a vehicle for making consolidated information available to anyone with an Internet connection, a standard browser application, and the proper security.

This section presents an overview of integrated delivery systems and managed care organizations as the primary organizers of health care data and a simplified discussion of the current structure and use of technology in the health care industry that facilitate the development of the Healthcare Information Trust.

#### A. Emergence of IDSs and MCOs

In 1994 the Institute of Medicine (IOM) published a study presenting observations and recommendations about "health database organizations" (HDOs).<sup>18</sup> HDOs referred to a variety of entities having access to or control of aggregate and individually identifiable medical data to be used for public release and public analysis.<sup>19</sup> At that time, the IOM recognized that true HDOs did not exist, although they would be emerging in the near future.<sup>20</sup> The IOM further recognized that HDOs would not be organizers of "primary medical records," nor were they "intended to be *the* major source of information about specific patients for the treating physician," but would be compilations of data for "secondary" uses.<sup>21</sup>

The IOM report also discussed at length the potential problems with HDOs, including making recommendations for their structure and regulation.<sup>22</sup> The report left much unsaid, however, about how widespread HDOs would become, their relationship to the primary consolidators of health care records, and particularly, the barriers to realizing truly "comprehensive" and

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<sup>18</sup> See INST. OF MED., *supra* note 17.

<sup>19</sup> *Id.* at 3.

<sup>20</sup> *Id.*

<sup>21</sup> *Id.* at 5; see also, Gostin, *supra* note 13, at 486 (providing a workable definition for "secondary" health care data uses).

<sup>22</sup> See INST. OF MED., *supra* note 17, at 1-26 (providing an executive summary of HDO issues and recommendations).

“inclusive” data sets across individuals and populations.<sup>23</sup> Citing specialized efforts to create HDOs with varying degrees of “comprehensive” and “inclusive” data sets,<sup>24</sup> the report assumed that significant HDOs would emerge in the future.

The IOM’s concerns and recommendations pertaining to HDOs are well founded and are very real considerations today. This Note, however, questions whether truly “comprehensive” and “inclusive” HDOs will emerge for the benefit of the public. Further, as will be discussed in Part III, this Note questions whether the existing organizations emerging as the focal collectors of health care data would be capable, absent some external regulatory or market pressure, of divulging their information or creating meaningful analysis for public consumption.

Today, most health care information is still held in “islands of data” throughout the extremely loose federation of health care providers and insurers; detailed medical information still primarily resides with individual providers (e.g., physician offices, laboratories, hospitals, pharmacies), employers, and health plans.<sup>25</sup> One need only observe first, the number of indi-

<sup>23</sup> See *id.* at 40-90 (lacking in-depth discussion of how HDOs will emerge and resistance to sharing data by provider and insurance organizations that might be primary collectors). “Comprehensiveness” means the data collected for individuals across different provider locations, and over time across episodes of care. *Id.* at 5. “Inclusiveness” means data collected across a variety of populations of individuals and across geographies). *Id.*

<sup>24</sup> See *id.* at 56-60 (citing a variety of developing HDOs in 1994).

<sup>25</sup> Gostin reports that:

The General Accounting Office estimates that the 34 million annual hospital admissions and 1.2 billion physician visits could generate the equivalent of 10 billion pages of medical records. . . . Information about a single episode of care could reside in the records of several different providers . . . . Further, there are no systematic operational models for the electronic storage of all aspects of health records.

Gostin, *supra* note 13, at 457 (citations omitted); see also William M. Sage, *Regulating Through Information: Disclosure Laws and American Health Care*, 99 COLUM. L. REV. 1701, 1723 (discussing the difficulties of compiling data from individual providers, the author notes that the “universe of potentially regulated parties below the level of the health plan is daunting”); RICHARD BRETAGNE ET AL., *LEADING THE WAY TO HEALTH INFORMATION EXCHANGE IN THE ELECTRONIC WORLD* (1999), <http://www.mahealthdata.org/mhdc/mhdc2.nsf/e214ac63ff65c87e852564580073a9fd/> (noting that “each individual has dozens of contacts with the health care system through various employers, many episodes of care, and multiple health plans, resulting in point-of-service ‘islands’ of patient information”); Lisa L. Dahm, *Using the DNA Profile as the Unique Patient Identifier in the Community Health Information Network: Legal Implications*, 15 J. MARSHALL J. COMPUTER & INFO. L. 227, 230

vidual physicians and health systems, and second, their largely insular relationships to understand the magnitude of the challenge.<sup>26</sup>

Nonetheless, several market trends point to the emergence of larger "islands of information." These include the consolidation of hospitals and other providers into "integrated delivery systems," (IDSs) and the emergence of "managed care organizations," (MCOs). Both of these organizations are collecting and consolidating far greater amounts of computerized medical information than ever before. These entities, arguably, emerge as the primary source and initial organizers of digitalized health information.

The 1990s have witnessed the rapid horizontal and vertical consolidation of hospitals, physicians, and other ancillary providers (e.g., skilled nursing homes, nursing homes, home health agencies, durable medical equipment providers) into IDSs.<sup>27</sup> Component parts of an IDS financially and legally incorporated, and integrated into one health system enterprise, may be far looser confederations of networks, or may be a combination.<sup>28</sup> Due to the variety of structures that these entities assume, conventional wisdom observes that if you have seen one IDS, then you have seen one IDS.<sup>29</sup> Nonetheless, these entities are similar

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(1997) (noting that health care providers encounter information that is only partially or totally inaccessible due to disparate information systems).

<sup>26</sup> See Sage, *supra* note 25, at 1723 (noting that the Joint Commission for Accreditation of Health Organizations (JCAHO) accredits 18,000 hospitals nationally, and there are over 500,000 physicians currently practicing in the United States); Dean C. Coddington et al., *Providing Capital for Physician Group Practices: New Opportunities for Hospitals*, HEALTHCARE FIN. MGMT., Dec. 1999, at 44 (noting that "of the more than 500,000 physicians in private practice in the United States, 75 percent are in solo practices or [small] single-specialty groups").

<sup>27</sup> See Edwin Fonner, Jr., *Milestones For Developing Integrated Delivery Systems*, J. OF HEALTH CARE FIN., Fall 1996, at 1 (discussing horizontal consolidation of hospitals, emergence of for-profit hospital systems, and physician group practice growth and the resulting development of vertically integrated IDSs); Robert Jantzen & Patricia R. Loubeau, *Risk-Sharing Integration Efforts in the Hospital Sector*, HEALTH CARE MGMT. REV., Mar. 22, 1999, at 83 (discussing the IDS as the "emerging organizational model" of healthcare delivery).

<sup>28</sup> See Martin P. Charns, *Organization Design of Integrated Delivery Systems*, 42 HOSP. & HEALTH SERV. -ADMIN. 411, 411 (1997) (discussing the theoretical evolution of IDSs through stages of horizontal and vertical integration).

<sup>29</sup> See *Integration Strategies in Transition: An Interview with Russell C. Coile, Jr.*, HEALTHCARE FIN. MGMT., July 1, 2000, at 37 [hereinafter *Integration Strategies*] (quoting industry expert recognizing that "the implicit concept of the IDS



in that they are all forging greater financial, operational, and clinical linkages among the disparate providers of health care in the face of the growth of managed care and increasingly competitive markets.<sup>30</sup>

Medical information sharing is essential to the provision of clinical care and administering a complex health care system.<sup>31</sup> IDSs have recognized the need for, and have begun to invest substantial capital in, integrating information systems to provide, at least theoretically, a seamless delivery of care—access to medical and health care administration information for providers throughout the IDS.<sup>32</sup>

MCOs also emerged as the second market player effectively consolidating vast amounts of individually identifiable health care information. An MCO, for the purposes of this Note, is a prepaid health care delivery organization that provides managed care insurance products, which can take a variety of forms. These organizations and products would include HMOs, preferred provider organizations, exclusive provider organizations, point-of-service plans, and physician-sponsored organizations.<sup>33</sup> This definition would include entities such as all models of HMOs, Blue-Cross/Blue-Shield plans now utilizing managed care insurance products, and other insurers, self-funded employers, and provider-organized networks insofar as they utilize (or subcontract for) managed care functionality and offer insurance products directly or through other organizations.

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will continue, but we probably will refer to them simply as systems with a small *s* because they will have such a variety of structures”).

<sup>30</sup> See, e.g., Jantzen & Loubeau, *supra* note 27, at 84 (finding that the major factors driving greater alignment among providers has been the growth of managed care and intensity of local competition).

<sup>31</sup> See Gostin, *supra* note 13, at 453.

<sup>32</sup> See Thomas M. McNamara, *Health Information Networks: Enabling Care Management in IDSs*, HEALTHCARE FIN. MGMT., Mar. 2000, at 30 (discussing the necessity of IDSs to integrate information systems to share managed care, cost and clinical information); Gwen Mousin et al., *IT Integration Options for Integrated Delivery Systems*, HEALTHCARE FIN. MGMT., Feb., 1999, at 53 (discussing the substantial capital investment required in integration, although challenging the certainty of “cost savings” through integration).

<sup>33</sup> For a more detailed description of these types of products/organizations, see Vickie Yates Brown & Barbara Reid Hartung, *Managed Care at the Crossroads: Can Managed Care Organizations Survive Government Regulation?*, 7 ANNALS HEALTH L. 25, 27-29 (1998).

Although MCOs have a long history in the United States, beginning with Kaiser Permanente plans in the 1930s,<sup>34</sup> it has not been until the last three decades that they have emerged in greater numbers and permutations.<sup>35</sup> By the 1990s, however, through growth and rapid market consolidation, they and their insurance products have become ubiquitous and formidable shapers of the competitive dynamic of the entire health care industry.<sup>36</sup>

Like IDSs, MCOs have realized the need for substantial information in order to manage the care of individuals and populations.<sup>37</sup> Many MCOs have expanded their data system capabilities beyond the basic claims processing functionality of indemnity insurers.<sup>38</sup> Substantial numbers of MCOs track and report data concerning cost and utilization, member satisfaction, Health Plan Employer Data and Information Sets (HEDIS) (or other care-quality report cards), specific disease incidence, population health, mortality rates, and health changes by condition.<sup>39</sup> MCOs also track data to support important clinical and administrative functionality, such as capitation rate analysis, provider credentialing, physician profiling, diagnostic episode analysis, and illness severity adjustments.<sup>40</sup> Critically important

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<sup>34</sup> For information about the history of Kaiser Permanente, see KAISER PERMANENTE, HISTORY: MORE THAN 50 YEARS OF QUALITY, at <http://www.kaiserpermanente.org/newsroom/history.html> (last visited Mar. 10, 2000).

<sup>35</sup> For information on the growth of HMOs from the 1970s to the mid-1990s, see INTERSTUDY, THE INTERSTUDY HMO TREND REPORT, 1978-1997 (1998); Brown & Hartung, *supra* note 33, at 26-27.

<sup>36</sup> See Grant T. Savage et al., *Beyond Managed Costs*, HEALTH CARE MGMT. REV., Winter 2000, at 93 (finding that although MCOs face an uncertain future if they continue to merely manage costs today, they will "dominate the national market for employer-based health care" through rapid consolidation, increasing market share of specific MCOs).

<sup>37</sup> See Sage, *supra* note 25, at 1726 (discussing the role of MCOs in consolidating provider data and the benefits and limitations of using MCOs for information disclosure); see also Arnold M. Epstein, *Rolling Down the Runway: The Challenges Ahead for Quality Report Cards*, 279 JAMA 1691, 1694-95 (1998) (discussing how increased information to consumers will help develop quality indicators).

<sup>38</sup> See Douglas R. Wholey et al., *The Diffusion of Information Technology Among Health Maintenance Organizations*, 25 HEALTH CARE MGMT. REV., Spring 2000, at 24 (reporting results of the information technology capabilities of 588 HMOs).

<sup>39</sup> See *id.* at 29. For a description of HEDIS, see NAT'S COMM. FOR QUALITY ASSURANCE, THE HEALTH PLAN EMPLOYER DATA AND INFORMATION SET (HEDIS), <http://www.ncqa.org/Pages/Programs/HEDIS/> (last visited Mar. 30, 2000).

<sup>40</sup> Wholey et al., *supra* note 38, at 26.

for the purposes of this Note, a large percentage of MCOs, sixty-eight percent, utilize or are creating "data warehouses" supporting managerial and clinical decision-support systems.<sup>41</sup>

## B. Creation of Clinical Data Repositories and Data Warehouses

Perhaps the most promising efforts by IDSs and MCOs today to organize and use the disparate pockets of information in their delivery system is the creation of clinical data repositories (CDRs) and data warehouses. CDRs and data warehouses integrate "numerous 'islands of information' . . . to allow users access [to enterprise-wide information] in a timely, effective manner . . . even if the [existing hospital's] operational systems are not standardized onto one [information system] platform or one physical device."<sup>42</sup> A CDR is typically oriented toward "patient-centered information" which can be updated in a real-time environment and organized so as to allow multiple access points and quick retrieval of information to support treatment decisions.<sup>43</sup> A CDR will contain individually identifiable health care data containing "patient demographics, lab results, scheduling information, medical record data, and images such as x-rays."<sup>44</sup> The amount invested in clinical data repositories by health care providers has been substantial.<sup>45</sup>

Data warehouses are also being developed by IDSs as well as MCOs.<sup>46</sup> Data warehouses may also contain individually identifiable health care information, though they are primarily oriented toward "aggregate views of the clinical, operational, and financial performance of the enterprise," in order to support, in a timely manner, reports supporting "administrative, managerial and executive decision-making."<sup>47</sup> Although less

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<sup>41</sup> *Id.*

<sup>42</sup> STRATEGIES AND TECHNOLOGIES FOR HEALTHCARE INFORMATION: THEORY INTO PRACTICE 16 (Marion J. Ball et al. eds., 1999) [hereinafter STRATEGIES AND TECHNOLOGIES].

<sup>43</sup> *See id.*

<sup>44</sup> *Id.*

<sup>45</sup> *See* John Morrissey, *Integration Sacrificed For Y2K Preparation*, MOD. HEALTHCARE, May 3, 1999, at 34. ("Sales of clinical repository systems surpassed \$1 billion for the first time in 1998, 43% more than sales in 1997 and 140% more than the \$459 million recorded for 1996. . . . In 1998, for example, the projection of \$631 million in sales was eclipsed by actual sales of \$1.1 billion. And in 1997, a projected volume of \$541 million was outpaced by the actual total of \$773 million.")

<sup>46</sup> *See* STRATEGIES AND TECHNOLOGIES, *supra* note 42, at 24-31.

<sup>47</sup> *Id.* at 17.

focused on individual patient or MCO enrollee data, these systems can support decisionmaking for population-oriented activities. MCOs have been able to use these data warehouses to facilitate management and clinical decision support and to more efficiently and accurately produce mandated reports for governmental agencies, employers, the National Committee for Quality Assurance (NCQA), and others, such as HEDIS.<sup>48</sup>

### C. The Internet Revolution and Individual Access to Medical Records

Not only are CDRs and data warehouses emerging in MCOs and IDSs as consolidators of health care information, but rapid developments in computer networking are also occurring. Internet access is quickly becoming a ubiquitous feature in most industries, and is becoming available to wider segments of the individual population.<sup>49</sup> This development has important implications for the sharing of digitalized medical records not only within IDSs, but with patients and other users of medical records. The eagerness of Americans to use the Internet for medical information is well documented.<sup>50</sup>

The standardization of Internet and browser technology can dramatically reduce the costs and difficulties of patients, and their health care agents, to access health care information about them.<sup>51</sup> If the Internet is used as a vehicle to disseminate certain information, as will be discussed below, it eliminates the costs of installing and maintaining remote software applications, which are specific to the software applications used by the

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<sup>48</sup> See *id.*; see also Wholey et al., *supra* note 38, at 28-29 (discussing services provided by information technology). Information about NCQA can be found at <http://www.ncqa.org/index.htm>.

<sup>49</sup> About 44.4 million households will be online by the end of 2000, up from 12.7 million in 1995, an increase of nearly 250 percent over five years; roughly 55 million Americans log onto the Internet on a typical day to send or read e-mail, get news and information or conduct business; and industry experts estimate that traffic on the Internet doubles every 100 days. Richard Drezen, *A Dot-Com World*, WASH. POST, May 17, 2000, at G1; see also Jill Young Miller, *The Web Grows Up*, ATLANTA J. & CONST., Aug. 14, 2000, at D1 (finding a dramatic increase in use of the Internet by women).

<sup>50</sup> Ninety-eight million Americans use the Internet each year to look for health information, which is up 44 million in the last two years. Edie Kasten, *Let the Surfer Beware: Use Health Information Found on Internet Wisely*, CHICAGO TRIB., Nov. 5, 2000, at C8 (citing an August 2000 Harris Poll).

<sup>51</sup> See STRATEGIES AND TECHNOLOGIES, *supra* note 42, at 32.

holder of the health care data.<sup>52</sup> Further, the use of an Internet browser to access health care information requires no additional training and expertise—that is, the training and expertise required to visit a web site such as “Yahoo” would translate to the ability to review medical records.<sup>53</sup> Finally, as demonstrated by the example below, software can be developed to access, integrate, and present information already stored in CDRs and data warehouses. Similar software can be integrated into an existing information infrastructure, minimizing additional data integration and compilation requirements.<sup>54</sup>

This technology is already being used successfully by IDSs. The University of Virginia’s early experimentation with the Internet in its Virtual Electronic Medical Record (VEMR) system is good example.<sup>55</sup> The University of Virginia used what it calls a Medical Records Generator (MRG) to organize various sources of information throughout its health care enterprise, creating a multi-layered, though non-dynamic, hyper-text markup language record of individual patient information including inpatient/outpatient financial account status, laboratory results, patient scheduling, patient demographics, radiological images, inpatient medications, insurance coverage, and discharge summaries.<sup>56</sup> Some of the information was compiled through a document management system that scanned documents in order to allow the end-user access to imaged information ranging from x-rays to a copy of the patient’s insurance card.<sup>57</sup> However, most of the information was compiled from existing health care information systems.

The University of Virginia experience is demonstrative of the existing capability of the Internet to revolutionize information access to medical record data. Although the information in the University of Virginia’s VEMR was non-dynamic, read-only records,<sup>58</sup> web technology is quickly becoming integrated into commercial information system products,<sup>59</sup> which will allow, in the near future, the ability to update information through

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<sup>52</sup> See *id.* at 24.

<sup>53</sup> See *id.* at 32.

<sup>54</sup> See *id.* at 33.

<sup>55</sup> See *id.* at 37.

<sup>56</sup> See *id.*

<sup>57</sup> See *id.* at 36-37.

<sup>58</sup> See *id.* at 40.

<sup>59</sup> See *id.*

a browser. Finally, the University of Virginia VEMR project cost the enterprise \$1.7 million over five years starting in 1993.<sup>60</sup> Although the authors caution that different organizations will have different financial requirements,<sup>61</sup> this level of capitalization would not be an insurmountable barrier to many larger health care organizations. Moreover, it is a cost that may decrease in the future, given the greater incorporation of Internet features in primary health care information system products today, including tools which access CDRs and data warehouses.<sup>62</sup>

The VEMR experience demonstrates that the use of the Internet can make information available to anyone with appropriate clearance, an Internet connection, and the ability to review medical information. In this respect, it is revolutionary, as it decreases the transaction costs to such a degree that anyone, including individuals and providers, can access and use digitalized medical records.

This section has demonstrated two of the three elements necessary for the emergence of a Healthcare Information Trust. First, the consolidation of greater islands of digitalized data in CDRs and data warehouses occurring today in IDSs and MCOs provides a starting, primary record source for comprehensive digitalized medical records—at least for records within individual IDSs and MCOs. Second, the Internet provides a feasible information network in order to practically and economically share digitized medical records from individual to consumers, their providers, and other third parties. The next section describes the emergence of a third requirement—the creation of a market for individually identifiable health care data where the individual is more than a passive participant.

## **PART II: LAW-ECONOMIC PROSPECTIVE ON HEALTHCARE DATA AND PRIVACY**

To understand the role of the hypothetical Healthcare Information Trust, it is critical to understand the economics of medical health care information within the ongoing medical re-

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<sup>60</sup> *See id.*

<sup>61</sup> *See id.* The current VEMR system allows users the ability to view medical record information. At this time, however, it does not allow the user to use the Internet browser to update information. In this sense, it is “non-dynamic” and “read-only.”

<sup>62</sup> *See id.* at 21-23.

cords privacy debate. First, a theoretical framework for using individually identifiable health care information for both “inclusionary” and “exclusionary” purposes will be set forth. Second, the economics of voluntarily divulged information will be described. Third, an observation of how this model has been applied to justify the creation of “default privacy rules” in health care information will be presented. This discussion will provide an understanding of the impact that the current proposed *Standards for Privacy* may have on medical information contained in IDSs and MCOs; further, it will lay the basis for understanding why the existing health care market fails to provide an efficient secondary market for health care information that provides both individual and collective benefit.

#### A. Inclusionary/Exclusionary Framework

In discussing data collected about individuals, it is useful to distinguish between “primary healthcare data” use and “secondary healthcare data” use. This Note addresses the latter of the two. In Gostin’s framework, “primary healthcare data” is used directly for the medical care of the individual, patient management, and financial reimbursement.<sup>63</sup> This is the direct use of information provided by the patient, and created by the health care provider, during the episode of care. Its use directly in the provision of and payment of care is, arguably,<sup>64</sup> implied in the contractual relationship between the patient and health care provider.<sup>65</sup>

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<sup>63</sup> Gostin, *supra* note 13, at 486 (describing “primary justification” uses and “secondary uses”).

<sup>64</sup> *See id.* at 486-87 (arguing against blanket assumptions about data disclosure without consent and need for compelling justification for non-consent releases).

<sup>65</sup> *See* Murphy, *supra* note 2, at 2387, 2402 (recognizing that information in commercial transactions is property and the right to the information “is a question of contract, either explicit contract, or . . . implied contract”). Murphy also recognizes that the analogous implied privacy standard between attorney-client and physician-patient, although ethical in origin, is “at bottom . . . a rule of contract.” *Id.* at 2408-10; *see also* Sage, *supra* note 25, at 1746-52 (discussing agency-related disclosure obligations); Gostin, *supra* note 13, at 508-09 (recognizing that an action for misuse of patient information by a physician can be based upon, among other theories, that of implied contract). A Uniform Commercial Code (UCC) drafting committee is discussing a revision of the Code to include implied warranties in information exchange. Resembling the implied warranty of fitness for a particular purpose existing in contracts for sale of tangible goods, the UCC may establish a national standard for information exchange. Kristin B. Keltner, *Networked Health Information: Assuring Quality Control on the Internet*, 50 FED. COMM. L.J. 417, 435-36 (1998).

“Secondary healthcare data” is the use of primary healthcare data for numerous ancillary purposes including, but not limited to, disclosures for education, regulatory purposes, commercial uses, research, and public health.<sup>66</sup> The comprehensive information enclosed in secondary healthcare data is very similar to that contained in what some would term “longitudinal medical records.”<sup>67</sup> This would encompass every record about a person’s health and care provision over all providers, all times, places, insurance coverage, or care delivery organizations.<sup>68</sup>

The promise of secondary uses of “semi-public”<sup>69</sup> digitized medical records, however, is not without serious threat to individuals. This is primarily through the potential for secondary uses of data to the detriment of individuals. Many authors have forcefully cautioned about the palpable effects on the individual of the digitalization and the inclusion of medical records within health care organizations, governmental agencies, and within any form of broader national electronic health care information infrastructure.<sup>70</sup> The wide-scale digitalization, consolidation, sharing, and data-linkages not only exacerbate existing threats to individuals, but raises a wealth of new issues pertaining to appropriate use of information. Gostin and Schwartz note that these fears are real, given the lack of virtually any federal restraints on secondary uses of the vast majority of individually identifiable medical information,<sup>71</sup> the ad-hoc nature of state legislation,<sup>72</sup> and the limited scope and constraining power of

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<sup>66</sup> Gostin outlines a number of uses for information tracked in currently existing “population-wide health databases,” including uses considered in this Note as “secondary healthcare data.” Gostin, *supra* note 13, at 467

<sup>67</sup> *See id.* at 458 (calling it “patient-based longitudinal health records”); *see also* Schwartz, *supra* note 11, at 52 (describing ‘longitudinal oriented lifetime patient summaries’).

<sup>68</sup> *See* Schwartz, *supra* note 11, at 52 (describing how with the use of online record management, one click of a mouse button can allow physicians to view a patient’s comprehensive medical record).

<sup>69</sup> *See id.* (describing the semi-public nature of on-line medical records).

<sup>70</sup> *See generally* Gostin, *supra* note 13 (providing, arguably, one of the most authoritative discussions of medical record privacy risks).

<sup>71</sup> *See id.* at 494-506 (1995); Schwartz, *supra* note 11, at 46 (explaining how the United States lacks any regulation prohibiting certain uses of health care information); *see also* Sheri Alpert, *Smart Cards, Smarter Policy: Medical Records, Privacy, and Health Care Reform*, HASTINGS CTR. REP., Nov.-Dec. 1993, at 13, 13 (noting commonly cited fact that video rentals have greater federal protection than do medical records).

<sup>72</sup> Gostin, *supra* note 13, at 506-08 (discussing state privacy legislation, including the “patient-provider privilege” and “disease-specific” statutes).



common law remedies for breaches of confidentiality (or other, similar tort actions), particularly after data is shared by the initial care provider for what may be, initially, legitimate purposes.<sup>73</sup>

The use of personally identifiable data as a market commodity has a nexus with the propensity of organizations to minimize uncertainty.<sup>74</sup> That is, absent economic, regulatory, liability, or contractual restraints, organizations will “greedily . . . scan and store as much information as possible” in order to identify and, if possible, eliminate risk.<sup>75</sup> The stakes are high; effective use of information, particularly in markets such as insurance, can mean profit-sharer returns or insolvency.<sup>76</sup> Information that can better identify “most-profitable” customers may be used to target those consumers, providing a significant competitive advantage.<sup>77</sup> Moreover, decreased transactional costs of compiling and analyzing data through the use of computers, and the increasing availability of individually identifiable information, is substantially lowering the economic barriers for such data use.<sup>78</sup> As Whitaker notes, many have come to speak of this as a contemporary “risk society.”<sup>79</sup>

<sup>73</sup> See *id.* at 508-11 (discussing common-law protection of health informational privacy).

<sup>74</sup> See REG WHITAKER, *THE END OF PRIVACY: HOW TOTAL SURVEILLANCE IS BECOMING A REALITY* 2-3 (1999).

<sup>75</sup> *Id.* at 45.

<sup>76</sup> See John V. Jacobi, *Canaries in the Coal Mine: The Chronically Ill in Managed Care*, 9 *HEALTH MATRIX* 79, 93 (1999) (stating that “because the risk assumed under modern, largely managed care-based health insurance is larger than ever . . . the incentives to pick and choose among potential insureds may be higher. [There is a strong incentive] to eschew risk selection”); see also, KENNETH S. ABRAHAM, *DISTRIBUTING RISK: INSURANCE, LEGAL THEORY, AND PUBLIC POLICY* 64-69 (1986) (explaining the intricacies of risk assessment in insurance law); see generally, DON PEPPERS & MARTHA ROGERS, *THE ONE TO ONE FUTURE: BUILDING RELATIONSHIPS ONE CUSTOMER AT A TIME* 123-124 (1993) (arguing that some customers have low or negative value and might be eliminated from sales efforts or product access).

<sup>77</sup> See PEPPERS & ROGERS, *supra* note 76, at 18, 95-97, 107-13 (arguing that information can assist organizations differentiate customers in order to gain increasing “share of customer”).

<sup>78</sup> Schwartz, *supra* note 11, at 23. Although the authors of *The One to One Future* suggest that the cost of “communication” and “information” will be zero, the dramatic decrease in, at least, the transactional cost of data collection, analysis and use is an underlying assumption of their vision of the “1:1” future. PEPPERS & ROGERS, *supra* note 76, at 6, 7, 24 (recognizing the decreasing costs of information processing asserting that these costs reduce “a thousand fold” every twenty years).

<sup>79</sup> WHITAKER, *supra* note 74, at 44.

The compilation of such data, coupled with the powerful incentives to use it, provide the ability to “exclude” individuals from a wide range of commercial goods (e.g., in our contexts, insurance, healthcare). Employers may utilize secondary-information from other sources to evaluate an application for employment and mortgage companies and other lenders already utilize information from credit reporting agencies. In the health care context, health information is compiled by companies, such as the Medical Information Bureau, to help insurers identify actuarial risks based upon previously submitted enrollment applications of individuals.<sup>80</sup>

Such exclusions based upon the use of secondary information raise a number of fundamental ethical issues: respect of human autonomy, respect for selfhood and person, and disruption of important intimate relationships.<sup>81</sup> They also raise significant utilitarian consequences such as disrupting the benefits of primary information disclosure for the provision of services (e.g., in our context, physician-patient services) by making participants less likely to share important information, and the positive externalities of full disclosure for collectively beneficial secondary uses of information (e.g., in our context, public health reporting).<sup>82</sup>

Putting a discussion of the negative affects of “exclusionary” uses of information aside for the time being, secondary information is also used for “inclusionary” activities. Inclusionary activities provide the opportunity to offer more highly customized and more selectively targeted consumer goods than ever before.<sup>83</sup> Perhaps the Internet is an emerging example of development in this area. By providing personal information to a web site, the web sites can “identify” the individual through “cook-

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<sup>80</sup> See Savidge, *supra* note 11 (discussing how MIB collects and sells information from insurance applicants); Reed, *supra* note 11 (same).

<sup>81</sup> See Gostin, *supra* note 13, at 513-15 (discussing ethical justifications for health information infrastructure).

<sup>82</sup> *Id.* at 511.

<sup>83</sup> See generally, PEPPERS & ROGERS, *supra* note 76, at 267-308 (discussing the concept of targeting customers, not merely niche products and catering to an organization's individualized understanding, through consumer data, of consumer needs); SETH GODIN, PERMISSION MARKETING: TURNING STRANGERS INTO FRIENDS, AND FRIENDS INTO CUSTOMERS 24-39, 60-69 (1999) (arguing that “permission marketing” will supplement interruption-based “mass marketing” and firms will develop greater dialogue with consumers, learning more about them, so that consumers trust firms and firms can education and tailor products to “their” consumers).

ies” and provide content that the individual desires, such as specialized news and consumer goods.<sup>84</sup> Just as likely, the web site will use this information to present advertisements targeted to the individual’s profile, which may be annoying or an outright intrusion.<sup>85</sup>

In the health care context, use of secondary information for “inclusionary” activities is already occurring. For example, mailing efforts by MCOs, physician groups, or public health agencies may be used to encourage mammography testing, prenatal check-up visits, sigmoidoscopy screening, immunizations, and other services which will benefit populations. These efforts compile information about populations, select individuals based upon demographic information, and use a variety of tools to encourage them to seek the health care service suggested.<sup>86</sup>

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<sup>84</sup> In the health care context, “cookies” are used by health-related sites. A survey by California HealthCare Foundation found that eighteen of twenty-one health-related web-sites it reviewed use “cookies.” JANLORI GOLDMAN ET AL., CALIFORNIA HEALTHCARE FOUND., REPORT ON THE PRIVACY POLICIES AND PRACTICES OF HEALTH WEB SITES 25 (Jan. 2000), available at <http://www.chcf.org/documents/ihealth/privacywebreport.pdf>. These enable the Web site to create a data profile of that user as the user visits the web-site over time. “[M]ost Web sites require users to forgo privacy in order to take advantage of the services being offered.” *Id.* at 15; see also GODIN, *supra* note 83, at 133-34 (describing a company called Imgis that uses cookies to track user data across multiple web sites in order to provide “customized” banner ads).

<sup>85</sup> See Bob Cook, *Identity Crisis: Personal Information Is Price Docs Pay for Free Online Services*, MOD. PHYS., July 1, 1999, at 44 (noting that the “free” products and information offered by web-sites to physicians are paid for by information that the physician offers explicitly and through the use of “cookies” and allows “advertisers to choose [which physicians] sees their advertisements” on the web-site); see also Janet Gemignani, *Who Sees Web Surfers’ Health Concerns?*, BUS. & HEALTH, Mar. 1, 2000, at 9 (noting use of cookies and banner ads to track patient information on health related web-sites has lead to privacy violations where nineteen of the twenty-one most trafficked health related web-sites violated their own privacy rules).

<sup>86</sup> For an example of such a program, see M. Renneker & H. Saner, *Low-Cost Flexible Sigmoidoscopy Screening: A Community Demonstration And Education Project*, 10 J. CANCER EDUC. 25 (1995); see also Anita J. Slomski, *Luring Patients in for Preventive Care*, MED. ECON., Dec. 22, 1997, at 51 (discussing computerized prevention tracking system where patients are sent reminders to receive preventative screens). Disease management programs are analogous, though more intensive, examples of how the use of specific healthcare information can improve population health by targeting individuals in specific disease states. See Billie Heister Waldo, *Disease Management Gains Acceptance—and Finds Its Legs—With Automation*, 18 NURS. ECON., 208, 208 (2000) (discussing the use of “evidence-based medicine and outcome data to improve the health of populations”).

Inclusionary efforts raise the same ethical and utilitarian concerns as “exclusionary” activities, if only less acutely. First, although ostensibly designed to provide the individual with a consumer option, they often use information without consumer awareness or permission. These efforts may be more about increasing services (and revenues) and less about population health. For example, efforts by pharmaceutical providers to encourage prescription refills have recently been attacked.<sup>87</sup> They therefore raise the same ethical issues regarding individual autonomy as exclusionary uses. Second, it is often impossible to differentiate truly “beneficial” information from the avalanche of “interruption”<sup>88</sup> marketing.

In short, “inclusionary” activities may also be problematic. Their value to the individual depends upon the utility they provide the individual and the individual’s desire to be communicated with. Indeed, in the case of inclusionary efforts, individuals may still be reluctant to disclose information about themselves for fear of unwanted communication.

It is also critical to note that information for “exclusionary” purposes can also empower consumers. For example, forcing MCOs to provide “report cards,” HEDIS report, and other quality-oriented studies is an exclusionary use of data oriented toward consumer choice. Individuals, or their expert purchasing agents (e.g., employers offering healthcare coverage) may use this information to differentiate insurers based upon quality, cost, or other measures. This also extends to efforts such as reporting of cost information and outcomes by hospitals, actions against individual physicians by Medical Boards, or physician profiles by health plans. Ostensibly, by providing these indicators, which may be required by governmental agencies or larger purchasers, consumers or their agents are better able to make choices about health care financing and delivery. In other words, individuals directly, or through their expert agents, can minimize their own risk and exclude plans and providers that measure less favorably.

From here on, exclusionary uses will be divided into two categories. Exclusionary uses by entities to deny individuals

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<sup>87</sup> See, e.g., Michael Slezak, *Chains Rethink Compliance After Patient Up-roar: Refill Reminders May Require Patient Consent*, AM. DRUGGIST, May 1998, at 10 (describing the controversy arising from pharmacies giving the names of customers to an outside firm, which sent prescription reminders to patients).

<sup>88</sup> See GODIN, *supra* note 83, at 24-29.

consumer benefits will be termed “first-order exclusionary uses.” Exclusionary benefits to benefit consumer decisionmaking in order to exclude organizations providing lesser benefit will be termed “second-order exclusionary uses.”

The inclusionary/exclusionary framework is important for our purposes because it is a simplified framework that will be used later to highlight the deficiencies of the current health care information market and the benefits of the Healthcare Information Trust. Specifically, it will be used to highlight the current market’s inability, in the face of default privacy rules, to optimize the value of secondary use health care data (particularly for individuals) as well as the advantages of the Healthcare Information Trust in realizing this value.

### B. Economics of Medical Records and Default Rules

Information is, arguably, the principal product purchased by patients when consulting health care providers; “information . . . is precisely what is being bought from most physicians, and, indeed, from most professionals.”<sup>89</sup> This information not only has a primary value to consumers as part of the bundle of goods and services purchased during an episode of care, but, as has been discussed, has a substantial secondary value. Two markets are quickly emerging in most consumer transactions today: first, the value of the initial products and services; second, and sometimes just as importantly, the secondary value created in the information concerning the transaction.<sup>90</sup> As both Murphy and Schwartz point out, at issue is who, in a voluntary contractual setting, should be the default owner of the secondary usage of the information. That is, should a default privacy rule (patient owner) or should a default disclosure rule (provider, MCO/insurer, third party as owner) prevail?<sup>91</sup>

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<sup>89</sup> Kenneth J. Arrow, *Uncertainty and the Welfare Economics of Medical Care*, 53 AM. ECON. REV. 941, 946 (1963); see also Schwartz, *supra* note 11, at 12-16 (showing that a core component of the delivery of medical care today is the use of digitalized medical records for “multifunctional” purposes).

<sup>90</sup> See Murphy, *supra* note 2, at 2402 (discussing secondary information as a “commodity that can be sold in a well-developed market”); Schwartz, *supra* note 11, at 23 (discussing how consumer preferences can be cheaply processed and combined with other personal data).

<sup>91</sup> See Murphy, *supra* note 2, at 2402-04 (discussing default privacy rules in the context of the value of privacy).

In the most simplistic situation where parties have equal bargaining leverage, information, and choice, this issue is far less complicated; presumably, with all transaction costs being low, the parties will be aware of the secondary value of this information and freely negotiate. The party most valuing the information will prevail and a price, including the cost of the information, will be incorporated into the transaction.<sup>92</sup>

Most, if not all markets operate with some distortions, requiring the law to recognize the most efficient default rule: privacy or disclosure.<sup>93</sup> The traditional economic view is that default disclosure rules are optimal in that “restrictions on the flow of information in the name of privacy are generally not social wealth maximizing, because they inhibit decisionmaking, increase transaction costs, and encourage fraud.”<sup>94</sup> Murphy and Schwartz argue, however, that some information markets, such as the one in health care, have significant distortions, leading to the conclusion that a default privacy rule is optimal. Further, as Murphy argues, these distortions justify more than a default rule, and require “information-forcing” disclosures to individuals.<sup>95</sup> There are four major classifications of these distortions: (1) effect of disclosure-default on the underlying socially beneficial activity; (2) a legitimate, non-fraud oriented “taste for privacy;” (3) asymmetrical information about the secondary market value of personally identifiable information; and (4) transaction costs.

Murphy promotes a default privacy rule in markets, such as health care, where disclosure default rules have the potential to substantially decrease the overall amount of primary information disclosed. Murphy recognizes that where individuals, fear-

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<sup>92</sup> See *id.* at 2403 (noting that the primary question is the size of transaction costs).

<sup>93</sup> See *id.* at 2404 (finding that “[t]he initial question is the ex ante question: Would the parties agree to disclosure of this sort? Or, using a more categorical approach: What is the appropriate default rule for transactions of this sort?”).

<sup>94</sup> *Id.* at 2382.

<sup>95</sup> *Id.* at 2416 (suggesting that “imposing nondisclosure obligations on the recipient of the information may be the best approach for certain categories of information”); Schwartz, *supra* note 11, at 73-74 (discussing the need for a default privacy rule when attempting to access patient information). Schwartz also notes that due to the unequal information and bargaining power between health care industry organizations and individuals, the health care industry organizations, covered by the default privacy rule, would be required to explicitly inform individuals of the secondary uses for which they seek to use individually identifiable healthcare information. *Id.* at 61-64.

ful of secondary disclosures, seek less of the underlying socially beneficial activity (e.g., provision of health care), or at least hide information useful for the efficient provision of the socially beneficial activity, the primary and secondary markets may be hampered.<sup>96</sup> This is the economic manifestation of the same “utilitarian” concerns expressed earlier in the Note.

Unlike previous economic views, Murphy recognizes the legitimacy of a “taste for privacy,” which may be oriented toward a true utility for privacy of certain sensitive information, such as that often arising in health care.<sup>97</sup> Although Posner would caution against privacy as a refuge for those who would hide their true nature in order to commit fraud,<sup>98</sup> health care is full of situations where privacy might be valued without any offsetting social/economic fraud cost. For example, although a default disclosure rule may be optimal for an individual’s credit record due the tangible possibility of fraud,<sup>99</sup> it is not clear that a default disclosure rule would be optimal for health care records that reveal certain socially stigmatizing procedures, such as a woman’s abortion history. Moreover, as Schwartz argues, the benefits of full disclosure of health care information, particularly genomic information, may be overstated in many cases.<sup>100</sup>

Therefore, given the socially sensitive nature of much of a person’s medical record, there may be a legitimate “taste for privacy” having no fraud implications.<sup>101</sup> Although this taste for privacy may not, in itself, balance the scales in favor of a privacy default rule, it is one more factor in its favor.

Health care also is fraught with asymmetrical information problems. In the context of a market for health care information, providers, MCOs, insurers and other third parties are in a position far superior to individuals in evaluating the true value of secondary health care information. In this way, firms take advantage of a “monopoly equilibrium,” exploiting consumer ig-

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<sup>96</sup> Murphy, *supra* note 2, at 2387.

<sup>97</sup> *Id.* at 2396.

<sup>98</sup> *See id.* at 2398 (noting that fraud inhibits a group from recognizing the heterogeneity of its membership, forcing the entire group to subsidize the unequal costs of its members).

<sup>99</sup> *See id.* at 2411-12 (discussing implied privacy contracts).

<sup>100</sup> For example, Schwartz argues that genomic information may only be used to reinforce employers “taste for discrimination.” Schwartz, *supra* note 11, at 25-26.

<sup>101</sup> Murphy, *supra* note 2, at 2396.

norance to gain the most favorable terms possible for the data use.<sup>102</sup> These entities do not disclose the value of the health care information. Further, they have the potential to use broad and vague waiver forms that consumers will often accept without question.<sup>103</sup>

Finally, these authors recognize the role of transaction costs in the selection of a default privacy rule. While Posner and the traditional law-economics school argue that transaction costs of gaining permission to use valuable information should weigh heavily in favor of adopting default disclosure rules, Schwartz and Murphy raise valid counter arguments. First, Schwartz suggests that transaction costs are decreasing; in particular, the cost of asking and tracking the preferences of consumers has become, if collected up front, minimal.<sup>104</sup> With modern technology, and with the fact that the product provider typically creates the "contract," it is not as costly for producers to inform consumers of the value of their information, allow consumers to specify their privacy interest, and track and safeguard this preference.<sup>105</sup> For example, the product provider may offer the customer a choice to opt-in or opt-out of the advertising.<sup>106</sup> For instance, individuals may choose to participate in their local supermarket's discount program whereby they allow their purchases to be tracked in exchange for discounted pricing.<sup>107</sup> The supermarket can then use the information for a variety of secondary uses, not directly related to the actual purchase, such as direct marketing through mailings and special rebate offers to encourage selection of more profitable products.

Second, Murphy recognizes that transaction costs are important in deciding which default rule is, relatively, the most efficient. He asks which of the two parties have the higher cost

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<sup>102</sup> Schwartz, *supra* note 11, at 61 (discussing legislation that requires notice of information that will facilitate competitive equilibrium between the individual and the health care industry).

<sup>103</sup> See Gostin, *supra* note 13, at 523-24 (discussing the theory behind routine disclosures); see also Schwartz, *supra* note 11, at 61, 64 (suggesting that the law needs to evolve to ensure that individuals are adequately informed before being allowed to consent to the disclosure of personal medical information).

<sup>104</sup> Schwartz, *supra* note 11, at 23-24.

<sup>105</sup> See Murphy, *supra* note 2, at 2413 (discussing the relative transaction costs of contracting out of default disclosure rules).

<sup>106</sup> See *id.* (noting that a merchant could sell consumer information simply by placing a "check-off box on the consumer-merchant contract").

<sup>107</sup> See *id.* (noting that the grocery merchant prominently display a notice concerning the information use).



in “contracting-out” of the default rule.<sup>108</sup> Undoubtedly, observing the various distortions in the health care market already discussed, individuals have a far higher cost than IDSs and MCOs in determining and structuring a solution to contract out of the default rule.<sup>109</sup> Therefore, relative transaction costs in most health care transactions also favor a default privacy rule.

Schwartz argues that a simple default rule is not enough and that a legislative or regulatory framework must follow health care information through all of its various uses, not just the initial transaction, because of what he describes as the multifunctional nature of the increasingly digitalized health record.<sup>110</sup> Schwartz recognizes that a default privacy rule would allow certain exceptions including safe-harbor uses “compatible with the original collection” (e.g., direct medical care, legitimate sharing between providers for health services, and financial transactions such as for billing purposes).<sup>111</sup> In addition, the privacy default would not be imposed for legally mandated reporting such as for public health, social service reporting such as for child abuse, and for certain medical research.<sup>112</sup> Adopting Gostin’s concept of information holders as “trustees,” the holders of health care information would also have explicit restrictions on the use of data requiring disclosures of only the minimum amount necessary, based upon legitimate need-to-know.<sup>113</sup>

The ability of a consumer to accept payment for release of her data rights assumes that the consumer understands and can enforce the bargain. One might question whether the typical supermarket shopper realizes that the pricing discounts she receives is in exchange for her buying pattern data. To this end, Schwartz would require that proposed legislation/regulations would also have substantial “information-forcing” and enforce-

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<sup>108</sup> See *id.* at 2412 (using the Coase Theorem to determine that the parties will allocate the right to the party who values it the most).

<sup>109</sup> See Schwartz, *supra* note 11, at 54 (discussing that the establishment of a default rule on privacy will lower transaction costs as fewer parties are forced to negotiate around the law).

<sup>110</sup> *Id.* at 14-17 (stating that by its very nature, the computer changes personal information into a fluid form and therefore the need of protections should be balanced with societal use).

<sup>111</sup> *Id.* at 59.

<sup>112</sup> See *id.* at 69.

<sup>113</sup> Gostin, *supra* note 13, at 524-25; see Schwartz, *supra* note 11, at 57-60 (outlining the necessary components of an effective statutory scheme for the control of medical data).

ment provisions. These provisions would ensure that the individual knows about her property rights in the data, can enforce this right, and can gain access to her records. The organization seeking to use her data for secondary purposes would be forced to provide a waiver form, designed in the regulations, which the individual could not be forced to sign.<sup>114</sup> In addition, Schwartz and other commentators recognize the critical need for health trustee accountability for the use of data and call for mandatory electronic audit trails describing all the access to, and use of, personally identifiable health information to assist individuals and their third-parties in policing appropriate use.<sup>115</sup> Finally, Gostin and Schwartz advocate the right of an individual to copy, review, and correct personal data.<sup>116</sup> This particular right may have substantial implications, which will be discussed later in this section.

### C. The Privacy Default Rule in Action – HHS Electronic Medical Records Standards

The Department of Health and Human Services (HHS) has released final rules for standards of privacy for individually identifiable health information.<sup>117</sup> These rules were released under the auspices of the Health Insurance Portability and Accountability Act of 1996,<sup>118</sup> requiring HHS, in absence of congressional action, to propose privacy rules for electronic records.<sup>119</sup> By-and-large, these regulations realize most of Gostin's and Schwartz's default privacy rule visions for uses of

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<sup>114</sup> See Schwartz, *supra* note 11, at 59-60 (discussing how the need to obtain medical consent of the individual before using or disclosing health care data will signal to the uninformed party about important contingencies causing negotiation for terms that better reflect the parties wishes may be added); Gostin, *supra* note 13, at 522-24 (discussing patients right's in their health information).

<sup>115</sup> Schwartz, *supra* note 11, at 63 (stating that one reason to advise health care consumers that people have accessed their records is to encourage "audit trails on a prophylactic basis"); Gostin, *supra* note 13, at 526 n.341 (discussing audit trails).

<sup>116</sup> Schwartz, *supra* note 11, at 62; Gostin, *supra* note 13, at 524.

<sup>117</sup> Standards for Privacy of Individually Identifiable Health Information, 45 C.F.R. § 164 (2000).

<sup>118</sup> Health Insurance Portability and Accountability Act of 1996, Pub. Law No. 104-191, 110 Stat. 1936 (1996) [hereinafter HIPAA].

<sup>119</sup> *Id.* § 264(c)(1) (providing "[i]f legislation governing standards with respect to the privacy of individually identifiable health information . . . is not enacted by [August 21, 1999], the Secretary of Health and Human Services shall promulgate final regulations containing such standards not later than [February 21, 2000]").

information where a “consent” is required for disclosures related to provision of care, payment, and health care operations and a written “authorization” is required for many others.<sup>120</sup>

For the purposes of this Note, there are several critical outcomes of the Murphy/Schwartz model and the HHS regulations. As Schwartz and Murphy both note, with the imposition of a privacy default rule, a new economic picture comes into clarity. In essence, the individual, for the first time, becomes a player in the emerging market for health care information. The IDS, individual provider, MCO or other health plan entity, and data clearinghouses are forced to negotiate with the individual in order to be able to use that information in a secondary market.<sup>121</sup> In fact, the covered entity must use an authorization form, which requires an explicit description of the proposed uses of the individual’s health care information.<sup>122</sup> Further, the form notifies the individual of his right to refuse to sign the authorization,<sup>123</sup> and the covered entity is barred from conditioning its services on the individual’s decision,<sup>124</sup> except in certain, specified situations.<sup>125</sup>

The HHS regulations also incorporate individuals’ access to their medical records.<sup>126</sup> Although the commentators regard this requirement as critical for ensuring accurate and complete information, and to ensure legitimacy and transparency in medical record management,<sup>127</sup> the requirement may have broader

<sup>120</sup> The final rule presents a separate “consent” for uses of healthcare information for the provision of treatment, payment and healthcare operation. 45 C.F.R. § 164.506.

<sup>121</sup> *Id.* § 164.514(e). The Final Standards for Privacy provide for an exception for certain types of marketing activities by a covered entity. *Id.* § 164.514(e)(2)-(f)(2). There are, however, significant restrictions placed on this marketing use. For example, it must come from the covered entity (or a business associate contracted to make the communication) and the covered entity must disclose if it received remuneration for the marketing. *Id.* § 164.514(e)(3). Such limitations, coupled with the agency and competition distortions faced by covered entities, as discussed *infra* Part III, make it unlikely that a strong secondary market could emerge.

<sup>122</sup> *Id.* § 164.508(c).

<sup>123</sup> *Id.* § 164.508 (d)(1)(iii)(B).

<sup>124</sup> *Id.* § 164.508 (d)(1)(i), (e)(1)(ii).

<sup>125</sup> *See id.* § 164.508(b)(4)(i)-(iv).

<sup>126</sup> *See id.* § 164.524.

<sup>127</sup> Gostin, *supra* note 13, at 524. “Transparency” is achieved by making individuals aware of their privacy rights in information and providing them a mechanism to guard against improper or erroneous use of the information. This is achieved by providing individuals (1) access to their medical information, (2) the right to modify

implications. Insofar as the regulations recognize an individual's property rights in her medical records, including the right to "copy"<sup>128</sup> these records, the individual, or her agent, may be given the right to disgorge the electronic records from the consolidated clinical data repositories of the IDS, MCO or data repository (each falling within the framework of the HHS rules), for use by the individual.

This ability could have striking implications for the feasibility of a far more dynamic health information market. This market, as will be envisioned in the last section, may allow the individual to use a new agent, the Healthcare Information Trust, to bypass IDS/MCO control over her medical records for secondary data use.

### **PART III: EXISTING HEALTHCARE ORGANIZATIONS AS HEALTHCARE INFORMATION TRUSTEES**

Having established the practical and technical possibilities of, at least, a non-dynamic longitudinal medical record, and having shown that a market for such data, in which individuals can participate, may become a reality, this third part questions whether existing market players, particularly MCOs and IDSs, are adequate organizers of the longitudinal medical record and brokers of personally identifiable health records on behalf of individuals. Although Schwartz and Murphy establish a protected role for individuals in this new market, they do not address this question explicitly.

The existing players, primarily MCOs, IDSs, are sub-optimal integrators of a true longitudinal medical record. This section will discuss the economic, agency and competitive market barriers to MCOs, IDSs, as well as possible industry cooperatives of IDSs and MCOs, emerging in this role.

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or correct this information; and (3) requiring the organization to have audit records detailing the use of their data. *See* Schwartz, *supra* note 11, at 61-63.

<sup>128</sup> *See* 45 C.F.R. §164.524(a) providing a "right of access to inspect and obtain a copy of protected health information about the individual in a designated record set" of a covered entity).

### A. Health Care Information Market Distortions in the Murphy/Schwartz Model

Returning to the theoretical inclusionary/exclusionary framework discussed previously, the Murphy/Schwartz model of the emerging secondary health care market is problematic. Negotiations between individuals and these entities allow these entities to purchase information primarily for inclusionary purposes and for first-order exclusionary purposes against the individual.

The Murphy/Schwartz model is not dynamic enough to realize second-order exclusionary uses of data for use by the individual. Historical medical information has substantial value in its aggregate form, across populations, to give individuals information concerning cost and quality of health services. As has been discussed, this is the driving force behind regulatory information disclosure.<sup>129</sup> Of course, an individual's ability to realize personal value in this information is contingent on a broader ability to aggregate this information with other individuals in order to analyze it for second-order exclusionary benefit. As will be discussed, MCOs and IDSs have little incentive to use this information for such purposes. For now, it is important to note that an individual, independently, has no ability in the Murphy/Schwartz model to realize this potential second-order exclusionary value in his medical information.

The Murphy/Schwartz model also suffers in that it does not recognize a variety of factors in the health care market that will confound effective valuation of health care data. It does not recognize the oligopolistic nature of the emerging IDS/MCO industry, the individual's lack of choice in MCOs, and the institutional inability of MCOs and IDSs to maximize the value of the secondary health care market data.

As previously discussed, the emerging MCO and IDS markets are consolidating at record pace. It is clear that, in most metropolitan markets, a handful of major provider networks/health systems are materializing.<sup>130</sup> An individual's ability,

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<sup>129</sup> See Sage, *supra* note 25, at 1715-20 (discussing competitively motivated disclosure laws).

<sup>130</sup> In reviewing fifteen communities nation-wide, authors conclude that, although the delivery of healthcare has not yet followed suit:

Markets are becoming more competitive. Providers that have always competed for individual patients on the basis of individual reputations and rela-

therefore, to shop for an IDS using the treatment of secondary health care information is, limited by the oligopolistic nature of the emerging market.

The selection process for MCOs may be even more constrained. Typically, non-Medicare/Medicaid individuals receive health plan benefits through their employers in this country—coverage that is typically in an MCO.<sup>131</sup> In most instances, choice of health plan coverage is substantially restricted; employers may offer only a few, and perhaps only one, MCO option.<sup>132</sup> In these situations, selection of a health plan based upon its use of secondary health care information use would be difficult, if not impossible, for the individual. Further, as will be

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tionships with other providers now are competing for blocs of patients on the basis of price and organizational reputation. In response to this, health care markets are consolidating at a rapid pace. Hospitals are consolidating most rapidly, and physicians least rapidly.

Paul B. Ginsburg, *The RWJF Community Snapshots Study: Introduction and Overview*, HEALTH AFF. Summer 1996, at 15; see also Linda T. Kohn, *Organizing and Managing Care in a Changing Health System*, 34 HEALTH SERVS. RES. 37, 42 (2000) (noting in a study that “[h]ospital consolidation was happening rapidly across all study sites. . . . [finding that] [i]n 10 of the 12 markets, over 50 percent of the volume was captured by the top four hospitals or hospital systems”). The future of the IDSs may be much more based upon strategic “e-business” connections, than outright ownership of all components of care. See *Integration Strategies*, supra note 29 (stating that “[t]he IDS based on full ownership is giving way to an IDS that relies to some degree on virtual relationships, or affiliations. . . . [and] [i]ntegration of those relationships probably will be achieved through some kind of e-health connection”); see also Stephen M. Shortell, *Slowly Remaking the U.S. Healthcare System*, 35 HEALTH SERVS. RES., 1, 1-2 (2000) (noting that hospital and institutional providers “are more evolved in the natural history of the organizational lifecycle than is the medical profession. For example, the hospital sector has changed from a cottage industry, up until the decade of the 1980s, to an entity that now comprises a high degree of consolidation: approximately 72 percent of the nation’s hospitals belong to a network or system”).

<sup>131</sup> See Alycia C. Regan, *Regulating the Business of Medicine: Models for Integrating Ethics and Managed Care*, 30 COLUM. J.L. & SOC. PROBS. 635, 637 (1997) (estimating that seventy-three percent of Americans who receive health insurance through their employers are enrolled in MCOs).

<sup>132</sup> See Diane E. Hoffmann, *Emergency Care and Managed Care—A Dangerous Combination*, 72 WASH. L. REV. 315, 349 (1997) (noting that “[a]ccording to recent studies, forty-five percent of individuals who get their health insurance through their employers are offered only one plan, and fifty-two percent of midsize employers” offer only one plan; moreover, where employees can choose among plans, good information about plan quality is lacking); see also Dayna Bowen Matthew, *Controlling the Reverse Agency Costs of Employment-Based Health Insurance: Of Markets, Courts, and a Regulatory Quagmire*, 31 WAKE FOREST L. REV. 1037, 1045-47 (1996) (describing four techniques employers use to cut health insurance costs).

discussed, the purchasing agents may not incorporate such considerations into their decisionmaking and may have contrary incentives against such restrictions of secondary use data.

Even if individuals were able to exercise a legitimate market choice concerning IDSs or MCOs based upon the consideration that they offer for secondary health care data use, these organizations will substantially undervalue the market price for secondary health care data. Neither IDSs nor MCOs are likely to offer this information to the full range of purchasers. For example, competing IDSs and MCOs are not likely to voluntarily offer their patient information, a valuable resource, to competing IDSs/MCOs, even if these organizations value secondary-use information more highly than the original compiling IDS/MCO. In addition, IDSs may be unsophisticated brokers of information themselves, lacking the administrative and technical expertise to maximize the value of this information for anything other than their particular secondary uses.

All of these imperfections suggest that most consumer decisions to waive protection of their secondary health care information will be a choice absent an optimal economic incentive to encourage waiver. That is, individuals will waive their rights to these data only if they, despite the HHS proposed rule protections, are indifferent to privacy concerns or are entirely uninformed about the value of their data. Moreover, even if IDSs or MCOs offer discounts or actual payments for this waiver, these payments will likely be less than the true value of this information in a more dynamic market. Although this market distortion, insofar as it over inflates the population of individuals selecting total privacy, may be a desirable balance according to some privacy advocates, it defaults to a sub-optimal use of this resource. This distortion, however, could create the opportunity for new market entities, such as the Healthcare Information Trust, that can better value and compete for the right to use secondary health care information.

### B. Agency and Competition Problems

Agency relationships in health care today are multifaceted and often ambiguous.<sup>133</sup> What is clear, however, is that agency and fiduciary obligations play a crucial role for unsophisticated

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<sup>133</sup> See Sage, *supra* note 25, 1752-64 (discussing ambiguities in the agency rationale).

consumers faced with insurance and health care provision choices.<sup>134</sup> The growth of IDSs and MCOs as primary organizers of longitudinal medical records and information brokers suffers from substantial agency/fiduciary problems, which may make them unattractive in this role for individuals. Returning, again, to our inclusionary/exclusionary framework, MCOs and IDSs lack incentives to aggregate data for second-order exclusionary purposes. Further, they have substantial incentives to use longitudinal medical records for first-order exclusionary purposes against individuals.

### 1. Agency Problems

Sage presents an interesting picture of the agency problems arising in today's health care system.<sup>135</sup> Prior to the current market-oriented managed care competition system, agency and fiduciary concerns were far less acute.<sup>136</sup> As cost control measures in health care financing have become a driving force in the delivery of services, a fracture has occurred between what Sage describes as the individual/professional and the collective/economic interests of both the health care financing and health care delivery stakeholders.<sup>137</sup> This is best illustrated by contrasting the traditional individual/professional agency and fiduciary obligations of the physician-patient relationship,<sup>138</sup> with the collective/economic fiduciary obligations imposed by the Employee Retirement Income Security Act (ERISA) to maximize the financial resources of the plan.<sup>139</sup>

The real picture is, however, far more muddled. Managed competition imposes new agency obligations onto physicians and other providers. Physicians may accept a role as primary care gatekeepers with multiple obligations to both patient (contractual and fiduciary) as well as proxy managers of subsequent referrals and health service utilization for MCOs (contrac-

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<sup>134</sup> See *id.* at 1743-45 (discussing the general nature of agency relationships in health care).

<sup>135</sup> *Id.* at 1743-64.

<sup>136</sup> See *id.* at 1744 (noting that the "rapid conversion of the American health system to managed care has magnified the need to safeguard agency relationships").

<sup>137</sup> *Id.* at 1752.

<sup>138</sup> See *id.* at 1752-57.

<sup>139</sup> See *id.* at 1744-45 (noting that "trustees administering ERISA plans owe their loyalty to the plan, not individual beneficiaries").



tual).<sup>140</sup> Specialist physicians may be contractors with MCOs where their payment, through withholds or other mechanisms, is based upon health care claims experience of their patients.<sup>141</sup> Moreover, as Sage notes, individual physicians may have even less control over patients in developing IDSs which, themselves, have a myriad of often conflicting agency relationships and financial incentives.<sup>142</sup> Indeed, IDSs may accept capitation agreements, which align their financial incentives toward collective/economic duties and away from obligations to the individual patient. These conflicting obligations are, therefore, not simply between the individual/professional duties of health care providers and the collective/economic obligations of health care financing entities; these two conflicting obligations have been, to a greater or lesser degree, internalized into health care deliverers.

This agency obligation challenge is, perhaps, even more exacerbated in the employer/employee and the beneficiary/government-as-payor relationships. As already stated, ERISA plans have a primary fiduciary obligation to the collective performance of the plan, with limited, if any, obligation to an individual's heterogeneous needs outside of the collective.<sup>143</sup> Moreover, the government, as payor in Medicare and Medicaid programs, has made substantial moves to control, or at least make more predictable, collective costs through Medicare HMOs,<sup>144</sup> Medicare+Choice<sup>145</sup> and state-driven Medicaid man-

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<sup>140</sup> See *id.* at 1745-46 (discussing how changes in managed care payment systems have motivated physicians to become more concerned with finance rather than patient care).

<sup>141</sup> See *id.* at 1745 n.151 (discussing how managed care has developed an extraordinary diversity of provider compensation mechanisms).

<sup>142</sup> *Id.* at 1754 (discussing how institutional processes such as the health plan can often effect overall quality when compared to physicians serving as individuals' agents).

<sup>143</sup> *Id.* at 1755 (citing 29 U.S.C. §§ 1001-1461 (1994)).

<sup>144</sup> See, e.g., Marilyn Moon & Karen Davis, *Preserving and Strengthening Medicare*, HEALTH AFF., Winter 1995, at 31-32 (discussing advantages and disadvantages of private sector ability to control Medicare cost through managed care programs and governmental focus on this strategy).

<sup>145</sup> See John K. Iglehart, *Bringing Forth Medicare+Choice: HCFA's Robert A. Berenson*, HEALTH AFF., Jan.-Feb., 1999, at 144, 149 (discussing HCFA's program improvement efforts).

aged care programs.<sup>146</sup> This demonstrates federal and state government's focus on its collective obligation.

Therefore, although such incentives encourage larger purchasers to force IDSs and MCOs to report information that allows them to differentiate by access, price and quality, this disclosure may well be used against individuals. Schwartz outlines several instances where this has already been the case in the employer-employee relationship including the use of health history in hiring decisions.<sup>147</sup>

## 2. Competition Problems

In addition to agency problems in the secondary health care information market, IDSs and MCOs face substantial barriers in seeking to use information for inclusionary and second-order exclusionary uses to benefit consumers. Although expanding the amount of information usable by consumers and providers is a well-regarded strategy,<sup>148</sup> regulatory disclosure schemes are inadequate to realize the full potential of a longitudinal medical record. Moreover, the structure of the MCO and IDS market, lack of adequate information incorporated in an individual organization, and lack of adequate incentives to coordinate information among competitors, may make it impossible to realize the benefits of a fully "inclusive" and "comprehensive" consolidation of longitudinal medical records in the existing health care market.

Notwithstanding the growing consolidation of MCOs and IDSs, the health care market is not monopolistic in most cases. Purchasers of health plan/MCO services and medical care often switch between various competing organizations.<sup>149</sup> This is quite pronounced in the employer health insurance arena where employees may frequently change plans at the end of coverage

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<sup>146</sup> See, e.g., ROBERT HURLEY & STEPHEN ZUCKERMAN, URBAN INSTITUTE, *MEDICAID MANAGED CARE: STATE FLEXIBILITY IN ACTION 8-11* (Mar. 2002) (discussing the origins of Medicaid managed care and motivations, among others, to make costs more predictable and to reduce program expenses).

<sup>147</sup> Schwartz, *supra* note 11, at 28-31 (explaining how increased disclosure may allow employers access to potentially harmful health information, which could increase health-related discrimination against employees).

<sup>148</sup> Sage, *supra* note 25, at 1704.

<sup>149</sup> See Peter J. Cunningham & Linda Kohn, *Health Tracking; Health Plan Switching: Choice Or Circumstance?*, HEALTH AFF., May-June 2000, at 158-59 (noting that seventeen percent of privately insured persons changed their health plan during the year prior to the survey).

periods. This mobility, often based more on employer plan changes than any other factors,<sup>150</sup> not only complicates the incentives to develop strategies for long-term population health performance,<sup>151</sup> but fractures the full record of individuals among competing MCOs and competing IDSs.

Some commentators observe that MCOs, due to their characteristics as large-population data-holders, are attractive consolidators of health care information.<sup>152</sup> Further, for at least as long as an individual is covered by the MCO, the MCO holds information about utilization across providers, thus integrating information regardless of where an individual is treated, providing a claim is submitted. MCOs, however, do not have the comprehensive medical record of patients.<sup>153</sup>

Likewise, although IDSs are beginning to compile greater clinical information, individuals may often seek care outside of a particular IDS, either with still-independent providers or with a competing delivery system. Thus, although they can increasingly integrate information within their own system, large holes exist in their records.

The current market lacks a mechanism or entity to coordinate secondary health care information across organizations. Sage suggests that a system of mandatory reporting of politically chosen cost, access and quality measures could address current inadequacy in use of health information for the benefit of consumers. However, such a regimen, even if it could realize Sage's criteria for success, still suffers from this fractionalization of information. That is, the reporting will not incorporate the full records of individuals, but rather, snapshots of the populations within MCOs or those using IDS services during the period. This brings us back to a vision of either a single, regional repository of a fully integrated medical record for individuals

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<sup>150</sup> See *id.* (noting that most plan changes were made for reasons other than consumer preference, including 33% due to employment change, 36.3% due to change in employer plan offerings; 16% changed because the current plan is less expensive; only 8% changed because their current plan has better services, higher quality, preferred doctors, or more convenient locations).

<sup>151</sup> See Sage, *supra* note 25, at 1777 (discussing how stable enrollment in a health care plan by an individual is necessary to facilitate practice-based research and to motivate health plans to focus on long-term performance).

<sup>152</sup> See *id.* at 1726-27 (discussing the advantages of centralized disclosure by health plans).

<sup>153</sup> *Id.* at 1727.

or, at least, agreements among competing systems to allow shared use of medical records.

MCOs and IDSs, however, lack the financial incentives to cooperate in such a manner. First, organizations realize the strategic value of health information they hold; they understand that the use of this information to differentiate themselves based upon "inclusionary" benefits to the individual would be lost if the information were released to a collective entity. Second, the information, particularly if it is comprehensive, has the potential to be used for second-order exclusionary purposes with uncertain consequences to the contributing organization. Although organizations perceiving their services to be higher quality may be more inclined to share, at least some organizations would realize the risk in such cooperation. The free-rider problem where only a few voluntarily share information would make it infeasible to implement a comprehensive longitudinal medical record or voluntary information disclosures under the current system without substantial governmental intervention.<sup>154</sup>

Moreover, the funding and structure of such cooperative efforts would be problematic. These efforts pose significant anti-trust implications, particularly where cost and pricing information may be shared.<sup>155</sup> But more than this, the practical ability of various competitors coming together and agreeing on anything more than the sharing of generic discharge or outpatient information, stripped of individually identifiable information, is probably not feasible. As one privacy advocate notes, "[c]ommand over information and its transmission will be the key to success in the capitalist world of tomorrow. The notion that this crucial resource will be [voluntarily] allowed to become a public good is idealism at its most inane."<sup>156</sup>

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<sup>154</sup> See René Bowser & Lawrence O. Gostin, *Managed Care and the Health of a Nation*, 72 S. CAL. L. REV. 1209, 1281 (1999) (describing how the government must take on some leadership role in the oversight of managed health care if non-competitive information sharing is to be successful).

<sup>155</sup> See generally FED. TRADE COMM'N, U.S. DEPT. OF JUSTICE, STATEMENTS OF ANTITRUST ENFORCEMENT POLICY IN HEALTH CARE § 3, <http://www.ftc.gov/reports/hlth3s.htm> (last visited Feb. 23, 2002) (discussing the antitrust implications of hospital joint ventures).

<sup>156</sup> WHITAKER, *supra* note 74, at 69.

### 3. Examples of Agency and Competition Problems

There are examples that demonstrate the agency and the competitive problems in the emergence of market collaborations to manage secondary health care data. The examples, discussed below, include: (1) the Medical Information Bureau; (2) the Massachusetts Health Data Consortium, Inc. and its Affiliated Health Information Network of New England; and (3) Health Action Council's Cleveland Health Quality Choice initiative.

The Medical Information Bureau is an insurance industry medical information clearinghouse.<sup>157</sup> The clearinghouse gathers information from approximately 700 insurance companies in the United States and Canada, which also fund its operation.<sup>158</sup> The companies that the Medical Information Bureau serve represent ninety-nine percent of the individual life insurance policies and eighty percent of health and disability policies issued in the United States and Canada.<sup>159</sup>

The Medical Information Bureau currently holds files on over fifteen million Americans.<sup>160</sup> It collects medical information from people who apply for insurance policies, which is then computerized and sold back to other participating insurance companies when they evaluate an enrollee for subsequent coverage.<sup>161</sup> Its files track over 230 coded medical conditions, and has other information concerning behavioral risk factors and limited financial credit information.<sup>162</sup>

As one privacy advocate noted, the Medical Information Bureau is not a service for individual consumers.<sup>163</sup> It is, however, an excellent proxy for the type of collaborative efforts most likely to spontaneously emerge from a competitive insurance-driven MCO market. The Medical Information Bureau operates exclusively to provide first-order exclusionary benefit for the insurance industry. It is fascinating to note the age of the organization. The organization was founded in 1890 as an informal group of insurance company directors meeting to avoid

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<sup>157</sup> Savidge, *supra* note 11, at D1.

<sup>158</sup> Reed, *supra* note 11.

<sup>159</sup> Savidge, *supra* note 11, at D1.

<sup>160</sup> *Id.*

<sup>161</sup> *Id.*

<sup>162</sup> *Id.* Examples of behavior risk factors are adverse driving records and whether the applicant fly small planes. *Id.*

<sup>163</sup> *See id.* (quoting Janlori Goldman, who notes that the MIB is "not interested in talking about what they do").

fraud and minimize financial risk.<sup>164</sup> This aptly demonstrates that, even in competitive markets, collaboration that holds a strong economic benefit to constituents will tend to emerge. However, there is no indication that the Medical Information Bureau might evolve beyond its current, and highly successful, role.

In a number of markets nationally, consortiums of hospitals and health systems, health plans, and governmental agencies have developed to create regional networks to share various medical information among health care industry constituents.<sup>165</sup> The Massachusetts Health Data Consortium, Inc. (Consortium) and its Affiliated Health Information Network of New England (AHINNE), recognized by the Robert Wood Johnson Foundation as one of a number of successful regional organizers of information, is a solid and progressive example of such consortium groups.

The Consortium was created in 1978 by a number of Massachusetts' major public and private health care organizations.<sup>166</sup> The objective of the Consortium was to facilitate, through a non-partial intermediary, the collection, analysis and dissemination of health care information.<sup>167</sup> Throughout its twenty-two year history, it has been extremely successfully in creating a variety of information reports,<sup>168</sup> products<sup>169</sup> and databases.<sup>170</sup>

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<sup>164</sup> *Id.*

<sup>165</sup> See Press Release, Minnesota Health Data Institute, Health Privacy and Technology Effort Receives \$2.5 Million National Grant for Five State Project (Jan. 11, 2000) (noting leading regional consortiums receiving Robert Wood Johnson grants to develop secure email protocol: Massachusetts Health Data Consortium (MHDC), Minnesota Health Data Institute (MHDI), North Carolina Health Information and Communications Alliance (NCHICA), Utah Health Information Network (UHN) and the Pacific Northwest-based Community Health Information Technology Alliance (CHITA) which is a program of the Foundation for Health Care Quality in Seattle), <http://www.mhdi/press-releases/2000/pr-1-11-2000.html>.

<sup>166</sup> MASSACHUSETTS HEALTH DATA CONSORTIUM: BACKGROUND AND HISTORY, at <http://www.mahealthdata.org/mhdc/mhdc2.nsf/Documents/Background> (last visited Mar. 21, 2002).

<sup>167</sup> *Id.*

<sup>168</sup> See MASSACHUSETTS HEALTH DATA CONSORTIUM: 20 YEARS IN HEALTH CARE, at <http://www.mahealthdata.org/mhdc/mhdc2.nsf/e214ac63ff65c87e852564580073a9fd/b88319ae14ce86268525663b0067b05e?OpenDocument> (last visited Mar. 21, 2002) (noting the 1978 establishment of a patient database on all Massachusetts residents permitting detection of patterns of disease and treatment; 1979 patient origin study determining where residents receive inpatient treatment; 1983 comparison of costs in the State's 111 acute-care hospitals; 1988 physician supply study; 1989

Today the Consortium encompasses an impressive list of institutional, technology, and partner organizations spanning the New England health care market.<sup>171</sup> In 1994 the Consortium established AHINNE in an effort to facilitate the development of a regional “electronic network for moving, storing and sharing patient information” and to “link providers, payers, employers, government agencies, physician offices and others and measure outcomes, analyze care costs and support care delivery.”<sup>172</sup>

The Consortium and its AHINNE effort have been impressive and should in no way be discounted. Their various data products and databases have, undoubtedly, provided a wide range of inclusionary and exclusionary benefits to the region’s health care users and expert purchasers, as shown by the wide range of utilization, cost, and public health reporting initiatives.

Nonetheless, the Consortium’s collected data, and market reports primarily focuses on aggregate inpatient discharge and outpatient procedural data.<sup>173</sup> The nature of the reporting, such as hospital discharge and outpatient procedure information, is likely to be a strong benefit to each of the market participants, particularly the participating hospitals, in identifying market-share, facility/service planning and cost comparisons that the member institutions can access for their own planning interests.<sup>174</sup> Moreover, the Consortium notes, in its case studies, a

studies of elders, mothers and children utilizing state data to monitor access, quality and cost) [hereinafter 20 YEARS IN HEALTH CARE].

<sup>169</sup> See MASSACHUSETTS HEALTH DATA CONSORTIUM: SERVICES & PROJECTS, at <http://www.mahealthdata.org/mhdc/mhdc2.nsf/Documents/Offerings> (last visited Mar. 21, 2002) (noting standard management reports on Insurer & Health Plan Analysis, Hospital and Physician Analysis, Case Mix Profiles, Charge Analysis, Market Share Analysis, Competitive Trend Analysis, Patient Origin by Town and Hospital, Discharge Disposition by Town and Hospital) [hereinafter SERVICES & PROJECTS].

<sup>170</sup> See *id.* (noting the Inpatient Database, Medicaid Ambulatory Database, Medicare Ambulatory Database, Ambulatory Surgery Database Project, Physician Licensure Database).

<sup>171</sup> MASSACHUSETTS HEALTH DATA CONSORTIUM: MEMBER LISTINGS, at <http://www.mahealthdata.org/mhdc/mhdc2.nsf/Documents/Members> (last visited Mar. 21, 2002).

<sup>172</sup> 20 YEARS IN HEALTH CARE, *supra* note 168.

<sup>173</sup> See SERVICES & PROJECTS, *supra* note 169 (noting the Inpatient Database, Medicaid Ambulatory Database, Medicare Ambulatory Database, Ambulatory Surgery Database Project, Physician Licensure Database).

<sup>174</sup> See MASSACHUSETTS HEALTH DATA CONSORTIUM: INPATIENT DATABASE, at <http://www.mahealthdata.org/mhdc/mhdc2.nsf/e214ac63ff65c87e852564580073a9fd/eaaffe2fb4ce0f77862565af0055ec51?OpenDocument> (last visited Mar. 21, 2002).

predominant number of uses for these competitive market comparison purposes.<sup>175</sup> It is questionable whether, without this mutual competitive benefit, the Consortium would exist. Moreover, as will be seen in the example of Cleveland Health Quality Choice, the long-term viability of the Consortium may also be questionable should the New England market consolidate into fewer IDSs and MCOs.

The Consortium, through its AHINNE initiative, has been leading an effort to establish a regional information infrastructure among participating providers and MCOs.<sup>176</sup> The group announced in 1996 efforts to create this network, including electronic access to medical records among its constituency.<sup>177</sup> AHINNE rejected the concept of “[r]egional centralized data repositories,” promoting, instead, initiatives to build “‘virtual’ network[s]” among key stakeholders in the New England market.<sup>178</sup> A consolidated clinical repository has been described as “costly, difficult to implement, and impractical for such a wide variety of data sources.”<sup>179</sup> Further a centralized data repository of more comprehensive medical records has been presented as a greater threat to confidentiality of medical records than business-to-business integration.<sup>180</sup>

AHINNE’s networking initiatives have been driven by operational data sharing needs, primarily between providers and payors, automating business to business needs (i.e., electronic data interchange of claims information)<sup>181</sup> rather than more far

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(noting the data elements and reporting available from the inpatient database; notably, cost information is not available and the orientation of standard reports is toward hospital planning: market share, market share trends, patient origination, and clinical service trends within hospitals).

<sup>175</sup> See MASSACHUSETTS HEALTH DATA CONSORTIUM, OUR CLIENTS TELL THE STORY (noting a “summary” of 1999 data requests revealing that of eleven listed, nine are for competitive market positioning of services), <http://www.mahealthdata.org/mhdc/mhdc2.nsf/e214ac63ff65c87e852564580073a9fd/9817b442d9f79843862565b000686012?OpenDocument> (last visited Apr. 20, 2000).

<sup>176</sup> BRETAGNE ET AL., *supra* note 25.

<sup>177</sup> See Eric Convey, *Group Touts Medical Info Access*, BOSTON HERALD, Mar. 29, 1996, at B30.

<sup>178</sup> BRETAGNE ET AL., *supra* note 25.

<sup>179</sup> *Id.*

<sup>180</sup> See also Convey, *supra* note 177 (noting the statement that it is easier to protect patient confidentiality under a system of connected networks than a central data repository).

<sup>181</sup> Julie Jette, *System to Standardize Medical Information*, PATRIOT LEDGER (Quincy, Mass), Mar. 31, 2000, at B6 (quoting Julia Cooney, an expert on the development of the electronic transaction standards from Deloitte & Touche, noting that



reaching networking of clinical records. At present, there seems little initiative to develop an infrastructure to facilitate more than transactional medical information sharing,<sup>182</sup> and certainly not the scope of longitudinal medical record sharing envisioned in this Note.

Cleveland Health Quality Choice began in 1989 by a group of the region's largest employers.<sup>183</sup> Participants included the Greater Cleveland Hospital Association, the Academy of Medicine and the Health Action Council of Northeastern Ohio,<sup>184</sup> the spearheading organization of the quality reporting initiative now representing fifteen major employers and the Council of Smaller Enterprises (COSE). COSE brought an additional 700 smaller businesses to group. In 1996 the groups represented more than 350,000 employees and dependants.<sup>185</sup>

Cleveland Health Quality Choice was created in order to identify and implement a "common set" of quality measurements of market hospitals and health systems.<sup>186</sup> The group created the quality measuring through work with physicians and statisticians, with the objective of comparing likely and actual outcomes, using elements such as "mortality, patient satisfaction and length of stay,"<sup>187</sup> controlling for severity of illness.<sup>188</sup> The employer groups have utilized the data to negotiate bulk contracts with higher quality facilities in certain specialties, decreasing costs to members.<sup>189</sup>

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business-to-business e-commerce as mandated in government regulations is the driving force behind AHINNE pilot program networking).

<sup>182</sup> See BRETAGNE ET AL., *supra* note 25 (noting as the only substantive initiative underway an effort to use secured email to share patient medical information).

<sup>183</sup> Christopher Dauer, *Nestle Exec Raps U.S. Health System*, NAT. UNDERWRITER, Mar. 18, 1991, at 21, 28.

<sup>184</sup> *Id.*

<sup>185</sup> See Grant Segall, *Doctoring the Way We Rate Hospitals*, PLAIN DEALER, Sept. 16, 1996, at B1.

<sup>186</sup> Dauer, *supra* note 183, at 28.

<sup>187</sup> Segall, *supra* note 185, at B1.

<sup>188</sup> See Joan M. Mazzolini, *Hospital Review Set for Release*, PLAIN DEALER, Mar. 18, 1993, at B1 (noting severity adjustments); see also Segall, *supra* note 185, at B1 (noting that despite criticisms concerning effectiveness of measurements, outside experts have reviewed the rating system finding it 'about the best that have been done anywhere').

<sup>189</sup> See Joan Mazzolini, *Area Businesses to Give Hospital Contracts Based on Performance*, PLAIN DEALER, May 17, 1996, at A1 (stating that the contracts went "to hospitals that have received good marks on report cards rating quality of care").

The efforts by the Cleveland Health Quality Choice, however, had been strongly criticized by participating health systems as early as 1993.<sup>190</sup> The Cleveland Clinic Foundation, one of the Cleveland institutions developing IDSs, increasingly attacked the program, calling for a complete overhaul.<sup>191</sup> As the Cleveland health care market began consolidating under increasing competitive and pricing pressures, commentators noted that the Cleveland Health Quality Choice reporting played an important role in ensuring quality of care.<sup>192</sup> Nonetheless, considerable criticism of the Cleveland Health Quality Choice and the Health Action Council's use of its data in designating Centers of Excellence for employer contracting continued through the mid to late 1990s.<sup>193</sup>

By the late 1990s, two IDSs had emerged in the Cleveland health care market—University Hospitals Health System of Cleveland and the Cleveland Clinic Health System.<sup>194</sup> Other budding IDSs either left the market, in the case of Columbia/HCA Healthcare Corp. (after its failed attempt to acquire Blue Cross/Blue Shield of Ohio),<sup>195</sup> or went bankrupt, as did the Physician Health Systems network.<sup>196</sup> Although the effectiveness of the Cleveland Health Quality Choice program in realizing true savings for its participants may be questioned,<sup>197</sup> many considered it to have increased quality in the Cleveland market.

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<sup>190</sup> See Mazzolini, *supra* note 188, at B1 (noting the Cleveland Clinic Foundation and University Hospitals of Cleveland were most critical of the reporting and that the Cleveland Clinic Foundation might withdraw); see also Segall, *supra* note 196, at B1 (accusing Quality Choice of mismeasuring risks and outcomes).

<sup>191</sup> Segall, *supra* note 185, at B1; see also Raquel Santiago, *Mixon Hits Hospital Rating Program*, CRAIN'S CLEVELAND BUSINESS, May 19, 1997, at 3 (discussing Cleveland Clinic director Malachi Mixon's criticism of the project for inaccuracy and expense).

<sup>192</sup> See Joan Mazzolini, *Hospital Grade Card Effort Wants Larger Role*, PLAIN DEALER, May 25, 1995, at B1 (noting how "having someone looking at quality helps keep everyone from the great temptation of cutting back too far").

<sup>193</sup> See Joan Mazzolini, *Hospitals Rebel at Quality Ratings*, PLAIN DEALER, Nov. 9, 1997, at B1; Raquel Santiago, *Hospitals Assail Designation System*, CRAIN'S CLEVELAND BUS., Oct. 13, 1997, at 3.

<sup>194</sup> Diane Solov, *Building Health-Care Empires*, PLAIN DEALER, Nov. 16, 1997, at H1.

<sup>195</sup> Diane Solov, *Survival Of Strongest Proves Operative Rule for Hospitals*, PLAIN DEALER, Mar. 9, 2000, at A1.

<sup>196</sup> See Regina McEnery & Diane Solov, *Amid New Efforts to Save Hospitals, Court Clears Way to a Shutdown*, PLAIN DEALER, Mar. 15, 2000, at A1.

<sup>197</sup> Troy Flint, *Health Program's Goal Difficult To Achieve*, PLAIN DEALER, February 26, 1999, at 1C.

The market consolidation, nonetheless, made it possible for Cleveland Clinic Health System to pull out of the program with its system hospitals.<sup>198</sup> The Cleveland Health Quality Choice program was “snuffed out” by this action.<sup>199</sup> Later, when the Health Action Council attempted to develop a new quality measurement program, the other major IDS, University Hospitals Health System, followed the Cleveland Clinic Health System’s lead and refused to participate.<sup>200</sup>

As the Cleveland Health Quality Choice experience demonstrates, the ability of larger Cleveland purchasers to provide second-order exclusionary benefit to its health care consumers has been largely frustrated as the market has consolidated. This may be due to lack of bargaining power in the wake of increasingly consolidated and powerful IDSs and the reciprocal inability to contractually disgorge primary information from IDSs and MCOs. The fact that an organization representing over 350,000 members would be unable to force IDSs to participate in quality management studies is a staggering observation. Is external monitoring of quality data simply irrelevant to health care decisions as the Cleveland IDSs argue? The Health Action Council does not think so, as evidenced by its continual effort to force health care information data from the IDSs.

Due to these structural barriers, Sage has argued for a governmental role in forcing the disclosure of health care quality information by MCOs and IDSs, in order to support private decisions<sup>201</sup> by individuals and, primarily, their expert agents. He does, however, recognize the substantial barrier for the political system working with health care industry stakeholders to develop such a structure, absent a clear consensus on the primacy of individual versus collective agency relationships,<sup>202</sup> and given the competitive issues discussed above. Although Sage concludes his observation about these barrier on an optimistic note, and suggests that the current ambiguities in agency rela-

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<sup>198</sup> See Joan Mazzolini, *Clinic Drops Out of Hospital Report Card Program*, PLAIN DEALER, Jan. 9, 1999, at A1 (discussing reasons for the Clinic pulling out).

<sup>199</sup> Troy Flint, *Hospital Program Snuffed Out*, PLAIN DEALER, Feb. 25, 1999, at C1.

<sup>200</sup> See Sandra Livingston, *Largest Hospitals Shunning Consumer Guide to Health Care*, PLAIN DEALER, May 21, 1999, at C1.

<sup>201</sup> Sage, *supra* note 25, at 1708-9.

<sup>202</sup> See *id.* at 1756-57 (stating that for disclosure to be an effective tool to improve health care, greater consensus regarding the obligations of the parties involved will be required).

tionships, in particular, may be simply transitional,<sup>203</sup> he provides no final solution to this dilemma.

For our purposes, and at least as far as the use of secondary health care information is concerned, the current health care market may be structurally incapable of optimizing the inclusionary/exclusionary benefits of this information without either trampling on an individual's interests in her own medical information or unduly restricting secondary medical information and its value. This disturbing possibility leads us to the final section of this Note, discussing the possibility of a new player in the health care information market—the Healthcare Information Trust.

#### PART IV: HEALTHCARE INFORMATION TRUST

Although a fictional organization, medical information trusts have been proposed in a similar context previously—at least as an abstract property categorization. Gottlieb has proposed the trust as an optimum property model for the protection of residual property interests of individuals in tissue samples collected in tissue repositories.<sup>204</sup> Gostin suggest that all holders of health care information have a fiduciary responsibility to the individuals to whom the information pertains, and are, therefore, 'health information trustees.'<sup>205</sup>

The purpose of this part is to present a possible framework for the Healthcare Information Trust, using the property concept of a trust as guide, and discussing some of its potential advantages and major barriers to its creation. The full scope of such a proposed entity deserves more detailed attention than provided in this final part. It is the author's hope that this Note will generate interest in fully exploring the possibilities of a Healthcare Information Trust.

##### A. Healthcare Information Trust Structure

As its name suggests, the Healthcare Information Trust is a legal trust that controls a person's individually identifiable medical information for the benefit of the individual. The trust,

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<sup>203</sup> *Id.* at 1756.

<sup>204</sup> Karen Gottlieb, *Human Biological Samples and the Laws of Property: The Trust as a Model for Biological Repositories*, in STORED TISSUE SAMPLES: ETHICAL, LEGAL, AND PUBLIC POLICY IMPLICATIONS 182 (Robert F. Wier ed., 1998).

<sup>205</sup> Gostin, *supra* note 13, at 524-25.

as a fiduciary agent, is assigned, by the individual, her property interest in her health care information held by any provider, health care plan or health care data clearinghouse. With the emergence of IDS and MCO clinical data repositories and data warehouses, the Trust could economically gain access to pre-consolidated individually identifiable information through the person's assignable right to copy her information. Practically, the Healthcare Information Trust may link into the IDSs' or MCOs' clinical data repositories or, if this is impractical, or resisted, force the periodic transfer of this individually identifiable medical and transactional information into the Healthcare Information Trust's own data repository. Although records will remain with the IDS or MCO for their own "primary" data use for the direct benefit of the individual's episode of care and for health care financial transactions, the Healthcare Information Trust, alone, would have the necessary waiver from the individual to use the data for "secondary" purposes. The creation of a Healthcare Information Trust recognizes that the current market is inadequate to realize protection for individuals in the secondary use of their health care information for purposes that provide them inclusionary benefit and second-order exclusionary benefits, while still protecting individuals from adverse first-order exclusionary uses.

Trust relationships are frequent in health care where an agent is needed to provide expert assistance. For example, the basics of the physician-patient relationship are felt, by some courts and commentators to incorporate the concept of fiduciary trust.<sup>206</sup> Other types of trust, such as those embodied in ERISA plans already discussed, are also examples.<sup>207</sup> These relationships arise in situations where a potential trust beneficiary would benefit by an expert agent, who, due to the experts capabilities and asymmetrical knowledge, can achieve a benefit for the beneficiary that the beneficiary might be unable to achieve alone. Further, fiduciary law, inherent in trustee-beneficiary relationships, has evolved recognizing that more vulnerable par-

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<sup>206</sup> See *Ritter v. Rush-Presbyterian-St. Luke's Med. Ctr.*, 532 N.E.2d 327, 331 (Ill. 1988) (disagreeing with other jurisdictions that allow ex parte communications between a treating physician and his patient's legal adversary); *Alexander v. Knight*, 177 A.2d 142 (Pa. 1962) (finding that doctor breached his fiduciary duty to his patient when he induced another doctor to breach a confidential relationship with that patient).

<sup>207</sup> See *Sage*, *supra* note 25, at 1744.

ties (beneficiaries) need to be protected from the more powerful agent.<sup>208</sup>

The concept of fiduciary is central to the concept of a Healthcare Information Trust and is its major advantage over other market players that might play this role. The trustee, when assigned the assets of the trust (i.e., individually identifiable healthcare information) would be obligated to make the trust property productive for the benefit of the trust beneficiary.<sup>209</sup> The trustee's obligation, unlike IDs or MCOs who may be subject to a variety of competing interests, is oriented only toward the interests of the beneficiary.

A trust, as a legal creation, is not difficult to implement. It can be created by the express intent of the settlor to establish it, and requires no special process or writing, so long as the purposes of the trust are adequately described in the trust agreement.<sup>210</sup> The settlor of the trust must have an ownership interest in the trust asset,<sup>211</sup> which would be satisfied by most state laws recognizing ownership in the information within medical records<sup>212</sup> and by the HHS regulations.<sup>213</sup>

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<sup>208</sup> Gottlieb, *supra* note 204, at 193.

<sup>209</sup> AUSTIN W. SCOTT & WILLIAM F. FRATCHER, *THE LAW OF TRUSTS* § 181 (4th ed. 1987).

<sup>210</sup> *Id.* § 17.1.

<sup>211</sup> *Id.* § 75.

<sup>212</sup> Paul V. Stearns, *Access to and Cost of Reproduction of Patient Medical Records: A Comparison of State Laws*, 21 J. LEGAL MED. 79 (2000) (tracing the evolution of common law and statutory property rights of patients in their medical records). The author concludes that the popular view has become that "[w]hen patients pay for treatment, whether directly, through health insurance, or via taxes for some type of subsidized care, they pay not only for diagnosis and treatment but also for information [thus, forming a property right in this information]." *Id.* at 104.

<sup>213</sup> Although not calling it a property right, per se, HHS noted in its proposed rule certain rights that patients may exercise, which have been maintained in the final rule:

We are proposing to establish several basic rights for individuals with respect to their protected health information. We propose that individuals be able to obtain access to protected health information about them, which would include a right to inspect and obtain a copy of such information. . . .

The right of access would extend to an accounting of disclosures of the protected health information for purposes other than treatment, payment, and health care operations.

Standards for Privacy of Individually Identifiable Health Information, 64 Fed. Reg. 59,917, 59,926 (proposed Nov. 3, 1999).

A critical issue for the Healthcare Information Trust would be its ability to financially sustain itself after initial funding. At this point, a mature market for secondary health care information has not yet been realized, despite evidence of secondary health care information use for a variety of commercial uses. Nonetheless, it may be possible for the Healthcare Information Trust to create a secondary health care market sufficient to fund its operations.

The HHS *Final Standards for Privacy* do not explicitly contemplate an organization such as the Healthcare Information Trust. Nonetheless, under the HHS regulations, information concerning individuals may be assigned to third parties, such as IDSs or MCOs, for secondary use purposes. This implies that an individual may assign her rights, not to an MCO, IDS or other existing health care organization, but to the Healthcare Information Trust. Once assigned, the information would be usable by the Trust for any purposes specified in the trust agreement, which would incorporate the waiver provisions required by the HHS *Final Standards for Privacy*. Since secondary uses of health care information by MCOs, IDSs, and other health care organizations is prohibited except with explicit authorization by the individual (and except as allowed in restricted circumstances by the final rule), such a trust agreement would provide the Healthcare Information Trust a virtual monopoly over its beneficiary population's information—a commodity that may become extremely valuable.

The structure also has the benefit that it can allow the Healthcare Information Trust, or its licensed agents, to act as an intermediary that can unlock the inclusionary and second-order exclusionary benefits of the data for the consumer, or the consumer's health care, or insurance purchasing agents. This is best described through example whereby pharmaceutical information would be "marketed" to trust beneficiaries.

First, the Healthcare Information Trust would allow individual beneficiaries the ability to choose the level of communication they wish from pharmaceutical companies. Based upon beneficiaries' individual and collective willingness to accept communications, the Healthcare Information Trust could offer a menu of demographic information to interested pharmaceutical companies interested in a precisely targeted population. The pharmaceutical firm might then identify its "target demographic," selecting from possibly hundreds of characteristics the

Healthcare Information Trust tracks, and pay the Trust for the privilege of marketing to its selected group *through* the Healthcare Information Trust. In this manner, no individually identifiable information—in fact, not even aggregated information—is passed to the pharmaceutical company. In such a model, the consumer benefits from access to inclusionary benefits, but individually identifiable health care information is safeguarded by the Trustee. Facilitated communication replaces the concern of “privacy” of information in the Healthcare Information Trust.

This, of course, raises several questions. First, why would enterprises, such as pharmaceutical companies, wish to purchase this type of access? Such “targeted marketing” efforts, and the willingness of enterprises to focus their marketing dollars on core customers, is not a completely novel concept. Far-thinking marketing experts have begun to observe the materialization of what some call one-to-one<sup>214</sup> or “permission-marketing.”<sup>215</sup> They observe that, as more and more information is collected on consumers, firms will have far greater ability to identify their optimal customers and to target them for super-specialized goods and services.<sup>216</sup> Others observe that the focus on mass interruption marketing,<sup>217</sup> such as television, radio, billboard and other advertisements, will be increasingly augmented by firms’ efforts, once they have identified their core customers, to customize marketing programs to much smaller, homogeneous groups or even individuals<sup>218</sup> and establish a level of two-way dialogue and trust with the customer.<sup>219</sup> These organizations will then focus on gaining greater market share

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<sup>214</sup> See PEPPERS & ROGERS, *supra* note 76 (highlighting the one-to-one theory behind consumer collaboration).

<sup>215</sup> See generally GODIN, *supra* note 83, at 60-69 (discussing permission and one-to-one marketing).

<sup>216</sup> See PEPPERS & ROGERS, *supra* note 76, at 3-7 (stating that the “old paradigm, a system of mass production, mass media, and mass marketing, is being replaced by a totally new paradigm, a one-to-one economic system”).

<sup>217</sup> See *id.* at 10 (calling it “awareness” advertising or “mass media”); see also GODIN, *supra* note 83, at 53-56 (discussing history of interruption marketing).

<sup>218</sup> See GODIN, *supra* note 83, at 64 (discussing techniques to turn customers into “supercustomers”); see also PEPPERS & ROGERS, *supra* note 76, at 10 (noting that 1:1 media are individually addressable).

<sup>219</sup> See GODIN, *supra* note 83, at 79-96 (discussing how frequency builds trust); PEPPERS & ROGERS, *supra* note 76, at 10-11, 51-94 (discussing the necessity of a two way dialogue with customers and customer “collaboration” as a means to facilitate this dialogue).



from its core, most profitable, customers.<sup>220</sup> Godin argues that in the future, dialogue with core customers will be an incredibly valuable commodity.<sup>221</sup>

Godin and Peppers & Rogers focus on the product-selling firms as the organizer of this "permission marketing" and producer-consumer "dialogue." This Note argues that due to the sensitivity of health care information and the property right that individuals have in their information, the Healthcare Information Trust might emerge as the facilitator of this interaction. Insofar as we are moving into a world in which firms will pay substantial sums to develop a "dialogue" (i.e., for the privilege of presenting product information and gathering information on consumers), the Healthcare Information Trust could use this market to sustain its administrative costs. Moreover, due to the *Standards of Privacy* rules and the Healthcare Information Trust's monopoly over its beneficiaries' data, these third parties would be forced to use the Healthcare Information Trust as an intermediary, or entirely forgo a truly "1:1 dialogue" with that population.

The Healthcare Information Trust could also be a superior investment vehicle for government in promoting population disease management and medical records research. Bowser and Gostin argue that "well considered delegations, incentives and regulations" might create partnerships between government and MCOs to promote "public health"<sup>222</sup> since MCOs are emerging as the key holders of health care information.<sup>223</sup> The authors contend that regulatory governmental intervention is best to solve such a problem and to focus investment in cross-competitor market initiatives to provide inclusionary and second-order exclusionary benefits to consumers.<sup>224</sup> Bowser and Gostin go so far as to suggest seed money for their initiatives, supposing support similar to the HMO Act of 1973.<sup>225</sup>

The Healthcare Information Trust could be, however, at least a comparable solution in promotion of inclusionary bene-

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<sup>220</sup> See PEPPERS & ROGERS, *supra* note 76, at 18-19, 123 (describing the logistics of applying the one-to-one theory to customer market).

<sup>221</sup> GODIN, *supra* note 83, at 74-78, 94-96, 131-42.

<sup>222</sup> Bowser & Gostin, *supra* note 154, at 1214.

<sup>223</sup> See *id.* at 1280 (discussing MCO development of comprehensive patient records).

<sup>224</sup> See *id.* at 1281.

<sup>225</sup> *Id.* at 1281-82.

fits (e.g., screening notices, collective management of diseases such as asthma in broader populations) as well as second-order exclusionary benefits (e.g., whole population HEDIS reporting). In fact, the government might be a primary purchaser of information from the Trust for government-funded clinical research, public health research, and to coordinate government-initiated inclusionary benefit initiatives for target populations. Moreover, the Healthcare Information Trust would far more effectively consolidate resources by providing a central repository of medical information, collection of which is occurring now on an individual, ad hoc, and highly inefficient basis. Much of the data used in federally funded clinical research is already collected in medical records,<sup>226</sup> but is difficult, extremely costly, or even impossible to access because of its location across the islands of data discussed in this Note. By refocusing resources on consolidation of primary sources through a Healthcare Information Trusts, duplication of efforts may be avoided.

Finally, the Healthcare Information Trust would also be far more responsive to market pressures than government-industry partnerships. The second order exclusionary information reported from the Healthcare Information Trust, or its expert agents, would be, ostensibly, the information most desired by individuals and their expert purchasers, rather than those selected by a political process subject to timing delays and to capture by special interests.<sup>227</sup> Therefore, this Note suggests that the government should explore investment in Healthcare Information Trusts if “seed money” becomes available, opening further funding options for the entity.

The second question is what benefit would such a trust arrangement have for consumers? First, beneficiaries might have direct financial returns once a mature secondary health care market emerges. Insofar as the revenue received by selling access to this information exceeds administrative costs, a premium or annuity might be paid to beneficiaries based upon the degree to which they allow themselves to be communicated with. Although this might not be a large sum and its availability is conjectural—it is an incentive that should not be ignored.

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<sup>226</sup> Gostin, *supra* note 13, at 457.

<sup>227</sup> See Sage, *supra* note 25, at 1708-09 (arguing for a political disclosure regime, but identifying major political process barriers).

Second, many individuals welcome beneficial, tailored marketing information. This may be particularly so if the information is relevant to a specific need, such as specialized health care services. Murphy noted a series of privacy studies conducted by Equifax, a credit reporting organization.<sup>228</sup> He commented on a study concerning consumer perceptions of direct marketing. When questions were biased toward the harms of direct solicitation, the majority of responses perceived direct marketing unfavorably.<sup>229</sup> However, when question bias was toward the potential benefits of direct marketing, the majority perceived direct marketing favorably.<sup>230</sup> Murphy validly observes that a minority, in either case, has a strong preference for privacy, notwithstanding benefits of direct marketing.<sup>231</sup> However, the study directly demonstrates that all individuals do not unequivocally reject such marketing.

The Healthcare Information Trust, or its expert agents might also provide other, non-commercial inclusionary benefits and second-order exclusionary benefits. The Virginia Electronic Medical Record demonstrates the power of this information to be used over the Internet. This has the advantage of providing an immediate, tangible, and demonstrable product to the individual. That is, the individual would have full access to a true "longitudinal medical record" for her own individual use. Further, to the extent that she uses health care providers from multiple IDSs or has transferred between different MCOs, her full record would be available to those outside of the particular IDS or MCO. In addition, she, and her expert agent, would be able to control the level and content of health care information disclosed. It should again be noted that this information would in no way replace the clinical and transactional information systems used by individual providers, IDSs, and MCOs; however, greater access to information in an Internet-based medical record system—particularly where a full longitudinal medical record would not be available across competing IDSs and competing unaligned providers—can substantially benefit care delivery. Some level of this benefit would likely be provided gratuitously, as the Healthcare Information Trust would need such a

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<sup>228</sup> See Murphy, *supra* note 2, at 2404-07.

<sup>229</sup> See *id.* at 2405.

<sup>230</sup> See *id.* at 2405-06.

<sup>231</sup> See *id.* at 2406.

real service product immediately to appeal to interested consumers as an incentive to sign the trust agreement.

Ultimately, the initial direct financial and inclusionary benefits to individuals will likely be dwarfed by the positive economies of scale created once the Healthcare Information Trust garners a large population. That is to say, that since the value of the information product offered to third parties (e.g., pharmaceutical companies or governmental agencies), or analysis of health care records (e.g., population HEDIS measures or provider proofing) will be in direct relation to the size of the beneficiary population managed by the Healthcare Information Trust, a critical mass of beneficiaries will be needed before Healthcare Information Trust is truly marketable. Therefore, the cost of initially organizing a critical mass of individual beneficiaries may be a substantial hurdle—if not prohibitive.

The Healthcare Information Trust would best be marketed through other organizations, such as employers, employer coalitions, and other entities (e.g., American Association of Retired Persons) representing large pools of health care consumers. These organizations would be in the best position to understand and value the second-order exclusionary benefits that such an organization might offer. For example, in Cleveland, there are over 350,000 potential beneficiaries in the defunct Cleveland Health Quality Choice program whose expert purchasers are still looking for a mechanism to provide these benefits to its membership. Although this would not eliminate subscription costs, it might make them manageable. This topic will be discussed further in the next section of this Note.

Considering the competitive and agency problems inherent in industry collaborations, most acutely demonstrated by the Cleveland Health Quality Choice experience, it is questionable whether more than business-to-business integration of medical health information will ever occur absent some other configuration such as the Healthcare Information Trust. There are, nonetheless, substantial barriers to the creation of a Healthcare Information Trust.

### B. The Healthcare Information Trust's Most Substantial Barriers

There are significant barriers to the Healthcare Information Trust emerging as a viable entity. This Note will address the

most challenging. Problems related to initial capitalization, ongoing funding, consumer indifference, and strong resistance by vested health care industry interests are the most serious.

The Healthcare Information Trust becomes independently financially viable only when it can achieve a critical mass of beneficiaries and promote its services in a mature secondary information market, with organizations willing to purchase access to its data or analysis. In a circular dilemma, a critical mass of beneficiaries is needed to develop its market; but to be financially viable and able to draw a critical mass of beneficiaries, it needs a more mature secondary information market in which to operate. The Healthcare Information Trust, therefore, needs to be funded in order to create an infrastructure, draw beneficiaries, and develop the secondary health care information market. This funding could be substantial.

Absent governmental intervention, large health care purchasers, such as self-funded employer groups and employer purchasing coalitions, must embrace this concept. Ideally, Medicare and State Medicaid programs would also follow suit, if the commercially oriented initiatives were successful. Larger purchasers, despite their own agency conflicts, might even perceive value in the Healthcare Information Trust model and provide seed funding and, most critically, a conduit through which the Healthcare Information Trust could promote its services directly to individuals. In fact, as the Cleveland Health Quality Choice experience described in the previous part of this Note demonstrates, it may be the only way to disgorge information from MCOs and IDs without governmental regulatory action.

To maximize the benefit of whole population inclusion, similar to the HDO concept of "inclusiveness," within Healthcare Information Trusts,<sup>232</sup> the government may also play a role in licensing. Looking to the utility industries as an example, an individual Healthcare Information Trust might be afforded a service monopoly over one or several market areas. This would have the advantage of ensuring one consolidated and uniform provider of this information within a geographic region, enhancing the value of secondary information reporting and inclusionary and exclusionary benefits to individuals and expert health care purchasers. Further, it might accelerate the development of the secondary health care market and provide, through monop-

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<sup>232</sup> See INST. OF MED., *supra* note 17, at 5.

oly pricing benefit, an enhanced return to beneficiaries and management company partners.

Consumer indifference may also be a substantial barrier. The same indifference that leads patients to undervalue their health care information in provider settings might make it difficult to effectively communicate the benefits of the Healthcare Information Trust. This might be partially offset by substantive large-purchaser partnerships with Healthcare Information Trusts. It may also be partially offset by the inclusionary benefits offered, particularly in early stages prior to the availability of dividend payments. Such a consumer barrier may make it expensive to educate populations about the benefits of such an arrangement and add to the funding needed to form the Healthcare Information Trust.

Since it is likely that a Healthcare Information Trust would need to be a non-profit organization "owned" by its beneficiaries, direct profit-sharing ownership in the Healthcare Information Trust would be limited. Nonetheless, the for-profit trust managers may be willing to provide funding, in hopes of long-term fund management contracts and other opportunities (e.g., using non-identifiable data for reporting or preferred "marketing arrangements" using the Healthcare Information Trust as intermediary). IDSs or MCOs, through third party administrators or other subsidiary management companies, might even realize the Healthcare Information Trust concept is in their own best long-term interest and offer such partnerships. This might occur after the Healthcare Information Trust has established a foothold. These relationships would, of course, be subject to the Healthcare Information Trust's primary fiduciary obligations to its beneficiaries.

An empirical analysis of the potential financial market in which a Healthcare Information Trust operates is outside the scope of this Note. It is recognized that, absent ongoing governmental subsidies, the feasibility of the Healthcare Information Trust depends upon this determination.

Finally, the resistance of current health care market constituencies to the Healthcare Information Trust cannot be underestimated. Although IDSs and MCOs may present a variety of barriers to the emergence of Healthcare Information Trusts, including political roadblocks, mere access to electronic medical records may be the largest single barrier that the Healthcare Information Trust might face.

Although the HHS regulations mandate individual access to “copies” of medical information, the regulations do not explicitly contemplate the type of electronic access required by the Healthcare Information Trust. The final privacy rule leaves such a transfer open, however. It states that the “covered entity must provide the individual with access to the protected health information *in the form or format requested by the individual*, if it is readily producible in such form or format; or, if not, in a readable hard copy form” or as agreed by the covered entity and the individual.<sup>233</sup> On the other hand, access only to paper copies of medical records and claims data would undoubtedly raise the transaction costs for a Healthcare Information Trust to an unmanageable level. Moreover, access to or transfer of electronic information in clinical data repositories or data warehouses in electronic format will require a substantial degree of technical collaboration between the Healthcare Information Trust and the target IDSs and MCOs. Even if provided financial compensation for such collaboration, it is not likely that MCOs and IDSs would work with Healthcare Information Trusts voluntarily. Moreover, even if MCOs and IDSs provide access to electronic data, they may well be inclined to frustrate Healthcare Information Trusts by imposing unreasonably “copying” charges, making electronic record transfers financially infeasible.<sup>234</sup>

The problem of industry reluctance, therefore, may also require some degree of governmental or health purchaser intervention. Judicial precedent giving an individual access to medical records in electronic format may achieve this. More likely, legislative or regulatory mandates might be required. Achieving these goals might also require substantial leverage by large health care purchasers with a vested interest in making the Healthcare Information Trust a reality. Again, business coalitions, such as Cleveland’s Health Action Council, which established the now defunct Cleveland Health Quality Choice, might be viable partners. Health Action Council’s experience may also

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<sup>233</sup> Standards for Privacy of Individually Identifiable Health Information, 45 C.F.R. §164.524(c)(2)(i) (2000) (emphasis added).

<sup>234</sup> One author tracks the use of copying charges as a means to frustrate access: [A]t Kinko’s, a nationally recognized copy business, the charge for copying is approximately \$ .07 per page, which includes the businesses’ staff making the copies. . . . [A typical] hospital’s price per copy, . . . \$ .83 per page, . . . seems patently unreasonable. Stearns, *supra* note 212, at 80 (discussing the mixed results of case law interpreting statutes requiring “reasonable” copying charges for medical records).

suggest that even larger purchasers will not have the leverage to force this collaboration without governmental intervention.

## CONCLUSION

This Note has differentiated between primary and secondary health care information use, recognizing the emerging value of secondary health care information compiled in health-care delivery and financing transactions. This Note has also presented IDs and MCOs as the primary organizers of health care information and recognized the increasing consolidation of information within clinical data repositories and data warehouses. Further, it suggests, through a discussion of medical record economics in light of imminent “privacy default rules,” competitive and agency problems in health care, and actual experience of MCOs and IDs, that existing organizations are not capable of fully exploiting secondary health care information for the benefit of individuals.

This Note also recognizes that the HHS *Final Standards for Privacy* provide an individual with an affirmative “property” right in her medical records. Through this property interest an individual may fully restrict her information from all but excluded or waived secondary uses. The individual might assign her rights to another entity, however, such as the Healthcare Information Trust.

This Note suggests that a Healthcare Information Trust could emerge as the expert agent for an individual’s secondary health care information. As an entity with an unfettered fiduciary obligation to maximize the benefit of secondary health care information for the individual, it would be situated outside of MCO and ID competition and agency limitations. Due to the Healthcare Information Trust’s unique ability to coordinate already consolidated health care information, its virtual monopoly over secondary use of health care data, its ability to ensure only limited disclosure of information, and its ability to use secondary health care information for the full range of inclusionary and second-order exclusionary purposes for the Healthcare Information Trust’s beneficiaries, it is a compelling vision. Nonetheless, barriers are apparent. Economic, practical, and political barriers still need to be fully explored and overcome should the vision be realized.



