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By Harold S. Luft

ANALYSIS & COMMENTARY

Advancing Public Reporting Through A New 'Aggregator' To Standardize Data Collection On Providers' Cost And Quality

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ABSTRACT Advocates for consumer-friendly public reporting on the performance of health care providers anticipate that, at some point, well-vetted and standardized measures will be widely available to help patients choose clinicians who provide the best care. However, achieving that goal would require assembling standardized data from many sources. Such an effort would raise concerns, including privacy considerations about having a single massive data repository; questions of how such an effort would be funded; and potential misuse of the data. This paper proposes creating a public-private data aggregator that would receive patient and provider data from payers that are deidentified in such a way as to remain useful for consumer-reporting and research purposes. The aggregator could be funded through fees charged to commercial users. Meanwhile, registered researchers putting their methods and findings in the public domain could access the data aggregator for free.

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Reports of health care provider performance aimed at consumers require standardized data drawn from many sources. Compiling such a massive data repository would raise concerns about how such an effort would be funded, as well as how to avoid potential privacy violations and misuse of the data.

This paper proposes creating a public-private data aggregator, or repository, that would receive deidentified patient data from payers. Researchers who put their methods and findings in the public domain could access the data for free. Others would pay for access, which would provide a revenue stream for the aggregator. Providers could choose to be identified in the data, and consumers who care about performance measures would probably prefer those providers to the others who remain anonymous.¹

The Agency for Healthcare Research and Quality's March 2011 Summit on Public Reporting for

Consumers offered a vision of consumer-focused reports on the quality of care of individual physicians. The summit brought together more than 100 consumer advocates, payers, policy makers, providers, and researchers to discuss what ideally should be, and plausibly could be, achieved by 2025 in the area of public reporting to markedly improve consumer choice and quality of care.

The goal is for patients to be able to use well-vetted and standardized measures to choose among clinicians to get the best care available. Some patients are already able to evaluate different hospitals' performance in treating selected conditions and performing certain procedures, using reporting tools such as Medicare's Hospital Compare website² and data compiled by the California Hospital Assessment and Reporting Task Force, or CHART.³

The lack of standardized data, measures, and reporting methods is one barrier to the effective

use of such reports. Indeed, collecting and appropriately using data from ambulatory care settings for provider-specific reports is a substantial challenge.⁴ However, performance measures are needed by providers and payers as well as consumers, and thus standardizing reports for consumers should not be the only goal. The infrastructure required to collect the data needed for performance measures and make the information available is too expensive to be used only for consumer-focused reporting.

A performance measurement infrastructure should do more than just help consumers make choices among providers. It should also continuously move the health care system toward improved care. This paper proposes a way of doing just that: creating a new data aggregator that would address both the self-serving resistance of providers to external assessments of their quality and the technical and research challenges involved in generating accurate and meaningful reports about providers.

Perhaps counterintuitively, such a data aggregator should not make it possible for consumers or others to identify specific providers without their consent. Consumer advocates assume that for providers to be identified in assessments, data reporting must be mandatory. This is only one solution to identified assessments, however, and it would be vigorously resisted by providers. And even if a law that mandated reporting could be passed, the information gained through such reporting would probably be of limited value for reasons discussed below.

In contrast, the approach outlined here offers a better chance of improving the quality of data, disseminating useful measures of provider outcomes, and improving the quality of care.

Into The Future

Reports on providers' quality are multiplying rapidly. Most are hospital-based and focus on relatively limited sets of measures. Assessments of the same hospitals across reports often differ, and even well-designed reporting motivates only a small fraction of patients to take action.^{5,6} One explanation for the small apparent impact of the reports is that the lack of standardization is confusing and dilutes the impact of the underlying information.

If only a single set of standardized reports is allowed, the exact nature and content of those reports becomes enormously important. Standardized reports require expert panels to develop the measures to be reported. To be clinically meaningful, the panels need to include people with special expertise, but many experts have ties to industry and are limited by the perspec-

tives of their discipline. Patient advocacy groups would naturally be involved, but many such groups have their own biases and do not report funding by industry.⁷ The politics that inevitably surrounds a centralized reporting effort inherently protects the status quo.

As computing power and data capacity grow, the cost of developing new measures to report on provider performance falls—as long as the underlying data are available. Instead of assuming that if only some suitably chosen committee could identify the perfect set of measures, consumers would then make wise choices among providers, we should facilitate the development of many new measures and reports and let consumers determine which they find most useful.

Meaningful performance reports—whether public or private, and whether intended for consumers or providers—require policies and processes ensuring that the underlying data are collected uniformly and made accessible to the report generators. Continued monitoring of the data to ensure its quality would be a substantial task. To sustain the overall effort, there must be a clear demand for better information by both consumers who want to select providers and providers who want the data for quality improvement. A viable funding model is also needed.

Standardizing The Data

Many steps are required to create a report on provider performance. Data must be collected from providers (and possibly patients) in a standardized manner, using common definitions. For ambulatory care, achieving this goal usually requires data from multiple providers involved in the patient's care. There also must be reproducible ways to attribute outcomes to providers.⁸

Performance measures must account for the patient's other clinical conditions and adherence to recommendations. There may be several measures of quality for any specific condition, and different people will value such measures differently. If the focus is on the performance of individual providers, reports must address the reality that most clinicians have too few patients with a given condition or requiring a certain procedure to generate statistically reliable measures based on such results as mortality or readmissions. Patient-reported measures of functional status and so forth have the potential to evaluate providers, but these measures raise important problems regarding standardization.

It is important to distinguish standardization of the underlying data from standardization of the information (and how it is presented). Data standardization is critical for a wide variety of

administrative and clinical purposes. Incentives for the “meaningful use” of information technology⁹ and requirements for reimbursement—such as using the new *International Classification of Diseases and Related Health Problems*, Tenth Revision (ICD-10)¹⁰—will go a long way toward achieving the goal of data standardization, although they alone will not be enough.

Development of standardized performance metrics for a broad range of clinical conditions is much more complex. Extensive research, preferably with considerable patient involvement on what outcomes matter to consumers, will be necessary for each of the many clinical conditions.

Even with perfectly standardized measures and comparable performance by clinicians, some will have better results than others in any given year just because of chance. With thousands of providers, there will be hundreds of such “chance winners”—even more, if there are multiple measures. To be meaningful, reports should be able to ensure that the top rankings are deserved, either because providers’ performance is consistent or because demonstrably better processes plausibly account for the better outcomes.

Although health is primarily affected by lifestyle factors and patient adherence, broad-based improvements in medical care will be largely attributable to physicians and other providers, not to consumers’ choice of better providers. In this sense, getting good health care is like ensuring that one has a safe car. People can use *Consumer Reports* to find the safest cars at any point in time, but manufacturers must redesign their products to make them safer. And to do so, manufacturers need much more detailed information than provided by the tests used by *Consumer Reports*. Driven by market pressures and *Consumer Reports* ratings, manufacturers mine such information from routinely collected data.¹¹

Reports credible enough for providers to use them to improve quality require access to data; the skills to process the data and create plausible, risk-adjusted models; and reasons to undertake the effort. Most public reports have been derived from routine administrative processes (claims) or mandated discharge abstract information not otherwise used by providers and therefore are of varying accuracy. Reports have typically been developed by academic researchers who are rewarded for pathbreaking research rather than for applying the same methods to ongoing quality improvement. Public and private services produce or repackage performance reports with variable fidelity and consistency, which gives clinicians not getting above-average scores plausible reasons to attack the reports’ methods or data.

Online consumer assessments such as Yelp or Angie’s List collect information from patients in almost real time. Their limited validity and reliability is offset by timeliness, accessibility, and pizzazz. Facebook’s “like” button makes it easy for consumers to see how their friends have assessed local providers.¹² Such assessments are almost certain to have a greater impact on the mass of consumers than dry reports, even if the latter have greater scientific validity. To increase consumers’ use of good data, we need high-validity assessments delivered by those with a business interest in attracting consumers. The role of accountable care organizations in this regard is discussed below.

What Data Are Needed?

There are numerous statewide reports on hospital performance based on all discharges, as well as reports from the Centers for Medicare and Medicaid Services. Unfortunately, both types of reports have disadvantages. The statewide reports include all patients seen at a hospital but do not include information from other providers treating the patient unless there are ways to link data across discharges. Data from Medicare—and other payers—allow such linkage across providers but do not include other payers. In addition to providing only a slice of a provider’s patient experience, this limitation exacerbates problems of insufficient sample size and inconsistent quality scores arising from assessments based on different patients.

To be valid, provider reports should include deidentified patient-level data on all, or nearly all, of a provider’s patients. However, the necessary information about those patients, such as comorbidities and subsequent complications, may be available only from a second set of providers who often are not professionally linked to the first provider. Collectively, the providers have the required information, but they have neither incentives nor mechanisms to share it with each other.

A solution lies with the payers—Medicare, Medicaid, and private insurers. So they can pay and adjudicate claims, payers routinely collect much of the necessary data on individual patients across multiple providers. However, payers currently have little reason to voluntarily share their data. In any case, bringing all such identifiable data together in a single site raises serious security concerns. The keys to solving this problem are making payers’ access to information that they find valuable dependent on their voluntarily providing their own data; and recognizing that the aggregator does not need patient identifiers—rather, it needs data with a

unique code for each patient assigned by the patient's payer.

Additional clinically relevant information can be added by the payers with little incremental threat to patient privacy.¹³ If suitably prepared by the payers and meeting clear standards for data quality, such data can be used to generate provider-based performance measures.

A Voluntary, Broad-Based Data Aggregator

The data aggregator should be a neutral entity controlled by a publicly appointed board, receiving a mixture of public and private funds, much like the Patient-Centered Outcomes Research Institute. The aggregator would acquire deidentified patient data from payers using data standards that would ensure that variables are uniformly defined and comparable.

THREE FUNCTIONS The aggregator would serve several functions. First, it would apply data assessment tools to ensure that the data meet the standards. In this regard, the aggregator would perform data quality assurance activities similar to those performed by the HMO Research Network's Virtual Data Warehouse to test the comparability of data to be shared by its member organizations.¹⁴

Second, as its name suggests, the aggregator would actually collect the data and deidentify it in appropriate ways. It would receive information on every clinical service provided, such as electronically reported lab results, with unique patient and provider codes. (Payers would not submit data on actual fees charged and amounts paid.) The aggregator would convert these data into a format that deidentified the provider (patient data would be deidentified before reaching the aggregator). The data would still provide patient-level results by provider, thus allowing process and outcome measures of performance.

Third, the aggregator would control access to the data, ensuring that the underlying data were not directly available to the public. Otherwise, the risk of reidentification would be too great. Providers are rightfully fearful that such data could be used to their detriment, even if they have above-average quality. In addition, payers would be unwilling to share their data with competitors, who might use the information to their own advantage.

The usual rationale for mandated collection of data is to make it freely available for public use. However, every organization with something to hide would lobby against such an approach, using legitimate privacy and security issues to make its case. Voluntary data sharing sidesteps this roadblock.

PROVIDERS' RIGHTS Although patient data arguably belong to the patient, providers may have some rights in data about the care they deliver. Such rights might preclude reporting on providers' performance without their consent, a legal issue that could take years to decide. But any such rights should not extend to withholding information about patients that could be used in the assessments of other providers. Payers would not have to submit data, but only those who did would be allowed to access the aggregator's combined data, a powerful incentive if Medicare and Medicaid participate. Payers' and providers' data submission and access agreement with the aggregator would not allow them to "cherry-pick" the data they submit.

Providers would be assured that anyone accessing the data had signed a data-use agreement promising not to attempt to reidentify any providers or patients. As with researchers seeking data from covered entities, potential users of the aggregator's data would specify the purpose for which the data would be used, the variables needed for generating a specific report, and the sets of providers to be included. The aggregator would provide the minimum necessary data to fulfill the request, strictly enforce this agreement, and deny future access to data by anyone not abiding by it.¹⁵

Individual providers could agree to have their results identified through the aggregator, either in general or just to specific data users. Those not agreeing would simply be listed as "declined to disclose." Report users could reach their own decision about the motives of providers who decline to disclose their identities through the aggregator.

The aggregator would also provide a mechanism for selective disclosure of the provider's identity to payers and health plans. This would be important because not all providers would agree to be identified in public reports with detailed measures of quality and resource use. Plans seeking providers in a particular market area could acquire data from the aggregator that do not allow the identification of specific providers. The plan could analyze these data and select some providers that it finds attractive. It could then ask the aggregator to communicate its interest to the desired, but as yet unidentified, providers. Those interested in discussing contract terms with the payer would disclose their identities through the aggregator, and direct negotiations between payer and provider would then commence.

ACCESS TO DATA FOR PATIENTS AND RESEARCHERS The Health Insurance Portability and Accountability Act of 1996 requires that access to the patient-level data necessary to gener-

ate reports be through enforceable data-use agreements, so the aggregator would deal only with organizations.¹⁶ In any case, very few consumers have the expertise to do their own analyses of such data, so they would need an intermediary to process the information and present it in readily usable formats.

The aggregator would directly facilitate the generation of improved measures and public reports. Researchers would be granted free access by the aggregator to deidentified data. In exchange, they would be obligated to make public the risk models they develop and the lessons they learned in using the data.¹⁷

Independent public or private report vendors could access the data for free, apply those public models, and offer consumer-focused information, also for free. If they charged clients, such as health insurers or physician groups, for more detailed reports—perhaps using their own proprietary risk models—they would need to pay the aggregator for the data access. Public reports could name only providers willing to be identified, but providers would not be allowed to withhold identifying information on a report-by-report basis. Although this practice would result in information being available on only a subset of providers, many patients would wonder about the quality of those providers who refused to be identified. Fees from data users would eventually support the aggregator's operations.

The accountable care organizations being developed for Medicare beneficiaries and others are not health plans that can lock in enrollees: Patients will need to be satisfied with their individual physicians, or else they will obtain care from other providers. This fact will increase the demand for information by accountable care organizations seeking to demonstrate that they provide enhanced value. These new organizations could attempt to use their own data for value reporting purposes, but this would typically reflect just a fraction of each physician's practice and would not convince consumers that the information was reliable. Many patients will prefer information from neutral third parties developing consumer-friendly applications that, at a low cost per user, can facilitate patient choices.

Different consumers place very different value on various indicators of quality, accessibility, patient experience, and cost. Some research suggests that clinical quality indicators may be less important than measures such as cost or accessibility.¹⁸ Other research points to the importance of subjective information, such as anecdotes and referrals from friends.^{19,20}

Patient reports of practitioner communication, follow through, and empathy may be reli-

ably measured. Such information is currently collected by some health plans. However, it is rarely aggregated across payers to reflect the entire practice of individual providers. Before accepting such data, the aggregator would need to audit the sampling and other processes used to ensure that the information is unbiased.

Operations And Interactions With Payers And Providers

The aggregator would be designed to be sustainable and expand the scope of data that it would access and make available. The aggregator could begin with currently available data, such as claims information that payers have, with diagnosis and procedure codes and both patient and provider identifiers. Only the latter are needed by the aggregator, which would replace even them by unique codes. Payers would replace the patient identifier with another unique code, allowing the aggregator to request clarification for a specific patient's data without knowing his or her identity.

Better measures of quality, however, need to go well beyond the data on claims forms and include information now presented only in medical records or elicited directly from patients. The aggregator would not be a global electronic health record. Instead, it would be analogous to research-focused data tables developed from electronic health records. Providers would maintain their own clinical and administrative systems, passing to the aggregator through payers only the necessary information on each patient.²¹ This information would not be everything needed for the care of the patient, but rather data from laboratory tests and other sources indicating desired or problematic outcomes—such as hemoglobin A1c values for patients with diabetes—or needed to produce risk-adjusted quality measures.

Payers might begin to demand such information to justify claims for payment. This is especially likely if Medicare's incentives to adopt certified electronic health records that demonstrate meaningful use⁹ lead to the infrastructure necessary to generate such data. Additional data collected for ongoing care—such as patients' reports on their functional status—and entered into the electronic health records could be passed on to payers and thence to the aggregator. There will be some variables that some providers—for example, those without an electronic health record system—cannot readily access. Those generating performance measures will need to assess how to deal with such missing data.

Importantly, the aggregator's functions would

intentionally be limited. It would not be charged with developing an ideal set of measures that meet all consumers' needs for choosing among providers, providers' needs for identifying better practices, or health plans' needs for identifying providers with whom to contract. The aggregator would simply focus on acquiring highly standardized and granular deidentified patient data from multiple payers and reconfiguring it to allow provider-specific assessments.

Conclusion

Consumer-focused reporting should incorporate feedback loops to ensure that data are current and reports are responsive to individual consumer preferences. Standardization of the underlying data is crucial. However, standardization of the specific metrics and reports is not. Changes in the delivery of health care, such as the introduction of accountable care organizations, are likely to have consumers and provider organizations clamoring for websites to provide measures of physician performance in user-friendly formats. If the data necessary for generating new measures and reports are made accessible in the appropriate manner, then the independent public or private researchers and vendors will be able to step in and meet this need.

When something such as information is freely available, no one is willing to pay for it. Government funding of standardized measure development and reports is vulnerable to special interest groups who can find legitimate statisti-

cal and privacy issues to buttress their arguments that certain measures are not ready for dissemination. In contrast, the data aggregator described in this paper would facilitate, but not produce, reports on individual providers, eliminating an easy target for obstructionists.

Organizations such as payers and accountable care organizations could use the data to approach the "positive deviant" clinicians—those achieving unusually good outcomes, who would be happy to be identified and thereby attract consumers. By not "outing" poorly performing physicians, the proposed aggregator mechanism would neutralize their opposition. By judiciously limiting access to organizations, the aggregator would have enforceable data-use agreements. And by charging fees for commercial use of the data, the aggregator would have a viable business model while allowing free access for researchers and developers of "open" models and measures and for those producing reports in the public domain.

The competitive pressures on accountable care organizations and similar organizations will lead to the generation of public reports with more-accessible formats and meaningful metrics to attract patients. Proprietary measures can't be outlawed, but the appeal of such measures would diminish as open source measures were developed by researchers who had free access to the aggregator's data. Consumers would then be able to use these quality reports to guide their health care decision making. ■

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NOTES

- 1 The aggregator would probably allow several levels of “willingness to disclose.” One level would probably be for general-purpose reports on quality measures to go into the public domain. A second level might be for reports on more detailed process, outcome, and resource use measures. These might both be more competitively sensitive and require more sophistication to use appropriately.
- 2 HHS.gov. Hospital Compare [home page on the Internet]. Washington (DC): Department of Health and Human Services; [last updated 2012 Jan 26; cited 2012 Feb 20]. Available from: <http://www.hospitalcompare.hhs.gov/>
- 3 CalHospitalCompare.org [home page on the Internet]. Oakland (CA): California HealthCare Foundation; [cited 2012 Feb 20]. Available from: <http://www.calhospitalcompare.org/>
- 4 *Provider* refers to the entity or person identified in a quality report. There was substantial, and unresolved, debate at the Summit on Public Reporting for Consumers regarding the focus of provider-specific reports. I use the term to refer to assessments of the performance of an individual physician or a small group of physicians who care for a specific patient, rather than assessments of the performance of all providers affiliated with an institution, such as a hospital or a large medical clinic.
- 5 Rothberg MB, Morsi E, Benjamin EM, Pekow PS, Lindenauer PK. Choosing the best hospital: the limitations of public quality reporting. *Health Aff (Millwood)*. 2008;27(6):1680–7.
- 6 Baker DW, Einstadter D, Thomas C, Husak S, Gordon NH, Cebul RD. The effect of publicly reporting hospital performance on market share and risk-adjusted mortality at high-mortality hospitals. *Med Care*. 2003;41(6):729–40.
- 7 Voelker R. Study: few advocacy groups disclose grants from drug companies. *JAMA*. 2011;305(7):662.
- 8 Care is often provided by a team of clinicians, making it impossible to know to whom the patient’s good or bad outcomes should be attributed. From the perspective of consumers trying to choose a provider—rather than the perspective of policy makers or providers trying to improve quality—performance measures should be attributed to the clinician to whom the patient is initially referred, if a specific problem is involved, or to the primary care physician normally responsible for coordinating a patient’s care. Measures and reporting levels may vary according to the purpose for which the data are being used. For example, a patient may want to know the functional outcomes of other patients six months after a joint replacement by particular orthopedic surgeons and their teams. The surgeon may want to know performance indicators for anesthesiologists and physical therapists who may be asked to join his or her team.
- 9 Centers for Medicare and Medicaid Services. EHR Incentive Program: overview [Internet]. Baltimore (MD): CMS; [last modified 2011 Dec 5; cited 2012 Feb 20]. Available from: <https://www.cms.gov/EHRIncentivePrograms/>
- 10 Centers for Medicare and Medicaid Services. ICD-10: overview [Internet]. Baltimore (MD): CMS; [last modified 2012 Feb 2; cited 2012 Feb 20]. Available from: <https://www.cms.gov/ICD10/>
- 11 Whiting R. Automakers rev up data-mining efforts. *Information Week* [serial on the Internet]. 2003 Mar 31 [cited 2012 Feb 20]. Available from: http://www.informationweek.com/news/software/productivity_apps/showArticle.jhtml?articleID=8700025
- 12 Smith SV. Marketers that you “like.” *Marketplace Tech* [serial on the Internet]. 2010 Nov 26 [cited 2012 Feb 20]. Available from: <http://marketplace.publicradio.org/display/web/2010/11/26/mm-marketers-like-that-you-like>
- 13 Results of a lab test are clearly more sensitive than simply knowing that a test was done and paid for. If the results indicated a disease, however, subsequent claims are almost certain to indicate the condition being treated. Under the terms of the Health Insurance Portability and Accountability Act of 1996, payers are allowed to obtain such data and are obligated to keep it both confidential and secure. They are allowed to share deidentified data for research and quality improvement purposes without the specific authorization of each patient.
- 14 Pardee R. Questions and answers about the virtual data warehouse [Internet]. Seattle (WA): HMO Research Network; [cited 2012 Feb 10]. Available from: http://www.hmoresearchnetwork.org/resources/tools/HMORN_VDW-Questions-and-Answers.pdf
- 15 As a further safeguard, the patient and provider codes would be changed for each data set delivered, making reidentification by the data recipient even more difficult. No system is “uncrackable,” but any organization attempting to relink data would place itself at risk of civil and criminal penalties.
- 16 Individual researchers might request access to the data, but they would almost always be affiliated with organizations that could ensure data security and had policies in place to prohibit attempts to reidentify the information.
- 17 Currently, each research team needs to master the subtleties of using certain data and variables because there is no venue or reward for sharing such information. The aggregator would provide such a venue. For more details about how the information derived would be made available, see Luft HS. Total cure: the antidote to the health care crisis. Cambridge (MA): Harvard University Press; 2008.
- 18 Tumlinson A, Bottigheimer H, Mahoney P, Stone EM, Hendricks A. Choosing a health plan: what information will consumers use? *Health Aff (Millwood)*. 1997;16(3):229–38.
- 19 Kaiser Family Foundation. 2008 update on consumers’ views of patient safety and quality information: summary and chartpack [Internet]. Menlo Park (CA): KFF; 2008 Oct [cited 2012 Feb 20]. Available from: <http://www.kff.org/kaiserpolls/upload/7819.pdf>
- 20 Carman KL, Maurer M, Yegian JM, Dardess P, McGee J, Evers M, et al. Evidence that consumers are skeptical about evidence-based health care. *Health Aff (Millwood)*. 2010; 29(7):1400–6.
- 21 Even without patient identifiers, someone with access to all of the aggregator’s data could identify a few patients by matching patterns of use and demographics with known external information. Firewalls and other security are designed to address the risk from hackers, which is no different than the risk for data held by providers. But because the aggregator would never receive patient names and addresses, reidentification would be rare, and its data would be a low-value target for hackers.

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In this month's *Health Affairs*, Hal Luft addresses a key step in developing meaningful and standardized quality measures for use in a serious public reporting effort: assembling massive amounts of provider- and patient-level data. To that end, he proposes creation of a public-private data "aggregator." Funded by fees paid by commercial users, this entity would assemble deidentified information to guard consumers' privacy and could be accessed at no cost by researchers who would place their methods and findings in the public domain.

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Luft's research has covered a wide range of topics, including medical care utilization; health maintenance organizations; hospital market competition; volume, quality, and outcomes of hospital care; risk assessment and risk adjustment; and health care market reform. He has authored or coauthored more than 200 articles in scientific journals and five books, including *Total Cure: The Antidote to the Health Care Crisis* (Harvard University Press, 2008).

Luft received both his master's degree and doctorate in economics from Harvard University, and he was a postdoctoral fellow at the Harvard Center for Community Health and Medical Care.