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## Section V:

# **A Vision for a 21<sup>st</sup> Century Health Care System**



## Chapter 16: An Information Infrastructure for New Jersey Health Care

### *Key Points*

- **The health care system severely lacks pertinent data and information needed to guide decision-making and to create incentives for provider accountability. A visionary information infrastructure is needed to overcome these barriers and realize the potential of a 21<sup>st</sup> century health care system.**
- **An information infrastructure is a key element of efforts to improve quality, address unjustified variations in clinical practice, and to measure and monitor hospitals' costs relative to efficiency benchmarks.**
- **Health information systems possess many of the characteristics of a public good – meaning the private sector will tend to under-invest in such a system. Public subsidies and mandatory participation are needed to develop and support sustainable information systems.**
- **Developing and sustaining a health information system is a very difficult task but one that holds great potential to improve health system performance. The State should form a commission charged with developing the framework and policies around the development of a regional health information system. Such a commission needs to engage many key stakeholders to overcome these challenges.**
- **To maximize effectiveness, a future health information system should be standardized, transparent, and easily accessible and should be managed by a public-private organization.**

It is fair to state that health care in New Jersey, in the United States and virtually everywhere in the world is rendered in a fog. People in that fog may be trying to do the best they believe can be done, but collectively they fall far short of the best that would be achievable with a lifting of that fog.

The fog in question is the lack of pertinent information that can, at once, guide decision making in health care, but also hold the participants in the health care sector accountable for their actions. It is also fair to state that, relative to other sectors in modern economies – e.g., the financial sector, the travel industry, and the retail industry, to mention but a few – the health sector tends to be a unique underachiever in this regard. It devotes relatively fewer resources to information systems than do other industries and, for the resources it does deploy,

achieves less. Much of the waste, fraud and abuse said to be part of modern health systems and considerable human suffering – in the midst of much succor and miraculous cures – can be traced to this lack of an adequate information system.

The persistent fog surrounding the delivery of health care is particularly disturbing in the face of current attempts to convert what hitherto had been known as “patients” into “consumers” who are expected to shop around smartly for cost effective care under so-called *Consumer Directed Health Care*. Unless strident efforts are made at long last to lift that fog through more widespread application of modern IT in health care, these “consumers” will resemble nothing so much as blindfolded shoppers thrust into department stores, there to shop smartly for wanted or needed items.

This chapter briefly explores the reasons for the lack of adequate information systems in health care, sketches the vision of a 21<sup>st</sup> Century health-care information system, examines how much of that vision has been achieved by now in New Jersey or is actively being pursued, and finally offers some recommendation to move New Jersey health care toward an information platform that adequately serves the state's people.

## I. The Imperative of a Health System Information Infrastructure

At the core of an efficiently functioning health-care system is an information infrastructure that enables the various decision makers in health care — patients, physicians and nurses, the executives of health care facilities, insurance companies and government officials -- to make decisions that result in timely and cost-effective health care. Remarkably, relative to other sectors in the economy, the health sector has been uniquely lagging in its use of available information technology (IT). In exploring the reasons why this is so, it will be helpful to divide the sector into its supply side and its demand side.

**The Supply Side:** As a general rule, suppliers in any economic sector will actively seek the information that helps them achieve their own goals, but otherwise will shun the transparency that might expose them to the brunt of full-fledged competition on price and quality as well as public accountability for the use they make of resources.

That penchant is not evil. It is normal and perfectly human. Therefore, the supply side in health care cannot be expected to develop the information infrastructure required for cost-effective, high-quality health care and full accountability unless those who pay for health care mandate it to do so.

**The Demand Side:** Remarkably, in health care the demand side of the sector has been and continues to be largely asleep at the switch. Patients and those who chiefly pay for health care (government and private

insurers) so far have been remarkably tolerant of a high variance in both the cost and quality of the health care they procure, where “high variance” is technical jargon for the phenomenon that excellent and shoddy quality and wasteful as well as cost-effective health care are permitted to exist side-by-side within the same health-care system – e.g., that of a single state or even a single community. Instead, the demand side of the sector has simply trusted the providers of health care to do the right thing and have been content to procure health care in the fog alluded to above.

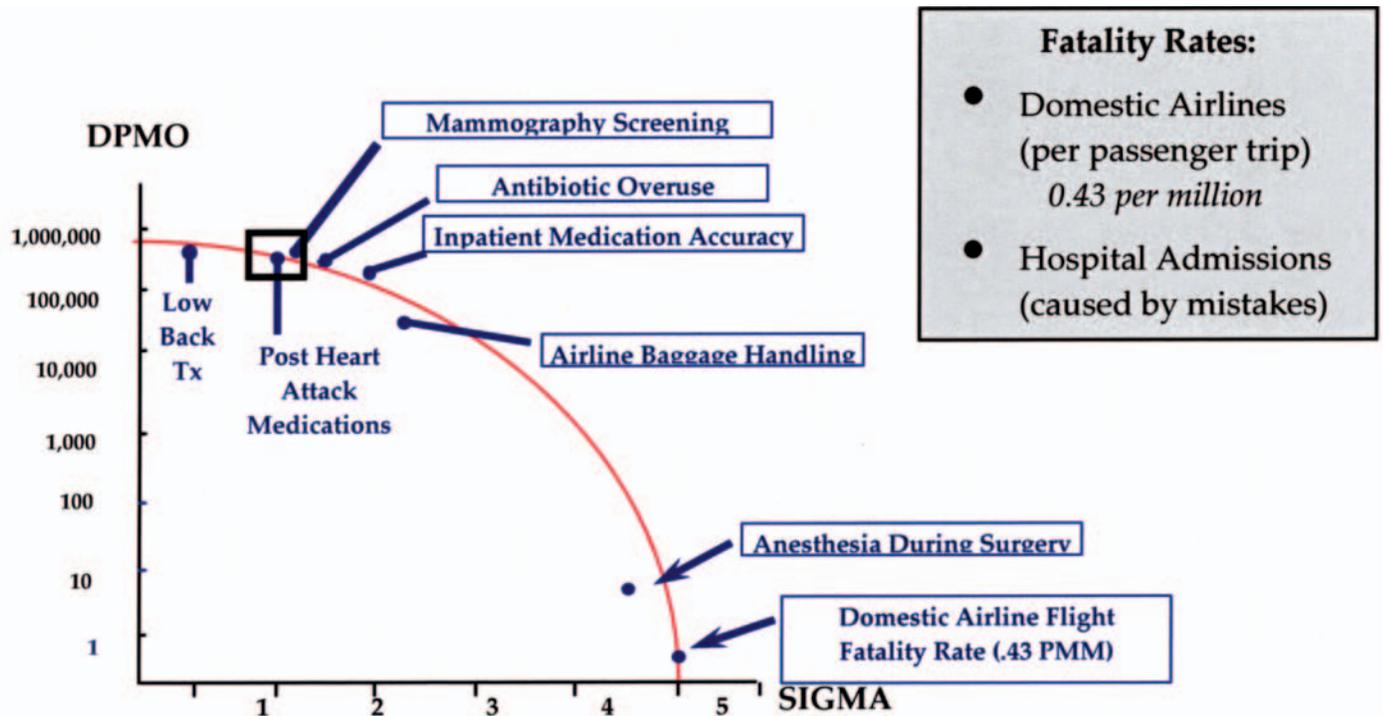
One can understand why patients, who usually are well-insured from the cost of health care, would not show much concern over the total *cost* of their care, as long as their out-of-pocket costs are tolerable. The patients' manifest indifference toward variations in the *quality* in health care, however, is nothing short of remarkable. The only sensible explanation is that so far patients have been kept ignorant of that variance, which has long been known to health policy analysts and at least some policy makers in the private and public sectors.

Why both public and private insurers have been so passive on this score, however, remains a mystery. It can flatly be stated that they could have served society better, but the economics of American health care have never compelled them to do so.

### A. High Variance in the Quality and Cost of Health Care

In the mid-1990s, for example, employee benefit managers at the General Electric Co. popularized the six-sigma chart shown below, indicating for a number of activities the number of defects per million opportunity for defect (DPMO), a metric used in six-sigma quality control. The chart indicated that more errors occurred in a number of medical treatments than in baggage handling by airlines, a notoriously error-prone activity. It is a quite stunning statement on the quality of U.S. health care, especially because Americans so often boast that theirs is “the best health system in the world.”

**Figure 16.1:**  
**The Quality Imperative: The General Electric View**



© 1994 Dr. Mikel J. Harry - V4.0 Source: Robert Galvin, M.D., General Electric Co.

At the end of the decade, in 1999, the prestigious Institute of Medicine (IOM) of the National Academy of Sciences published its landmark study *To Err Is Human: Building a Safer Health System*, in which the Institute’s panel of experts estimated that somewhere between 44,000 to 98,000 Americans died prematurely in hospitals as a result of avoidable medical errors, very frequently errors in the administration of drugs. Earlier in the decade, Lucien L. Leape, M.D. of Harvard University had likened these premature deaths due to medical errors in a seminal article published in the *Journal of the American Medical Association* to “the equivalent of three jumbo-jet crashes every 2 days.”<sup>169</sup>

The IOM’s 1995 report was followed, in 2001, by the Institute’s *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century*. A passage in the Executive Summary is instructive for present purposes:

The health care system as currently structured does not, as a whole, make the best use of its resources. ... A highly fragmented delivery system that largely lacks even rudimentary clinical information capabilities results in poorly designed care processes characterized by unnecessary duplication of services and long waiting times and delays. And there is substantial evidence documenting overuse of many services – services for which the potential risk of harm outweighs the potential benefits. What is perhaps most disturbing is the absence of any real progress toward restructuring health care systems to address both quality and cost concerns, or toward applying information technology to improve administrative and clinical processes (p. 3; Italics added).

Apparently, there has not been much progress since 2001 either. In a paper entitled “The End of the Beginning: Patient Safety Five Years After ‘To Err is Human’,” Robert Wachter observes that

<sup>169</sup>Lucien L. Leape, “Errors in Medicine,” *Journal of the American Medical Association*, 272(23) (December 21, 1994): 1851-58.

**Table 16.1:**  
**Blue Cross Blue Shield Outcomes Study for Tertiary Centers**

	Blue Distinction Centers		All Other Centers	
	Mean	Maximum	Mean	Maximum
<b>Short-term Major Complications from Bariatric Surgery</b>	<b>5%</b>	<b>8%</b>	<b>7%</b>	<b>37%</b>
<b>Heart Transplant Patient One-Year Mortality Rate</b>	<b>11%</b>	<b>30%</b>	<b>19%</b>	<b>57%</b>
<b>Inpatient Mortality (Heart Attack)</b>	<b>7%</b>	<b>15%</b>	<b>9%</b>	<b>40%</b>

Source: Data provided by Nat Kongtahworn, Director, Network Strategies, Office of Clinical Affairs, Blue Cross Blue Shield Association.

Since 1999, there has been progress, but it has been insufficient. Stronger regulation has helped, as have some improvements in information technology and in workforce organizations and training. Error-reporting systems have had little impact, and scant progress has been made in improving accountability. Five years after the report's publication, we appear to be at "the end of the beginning."<sup>170</sup>

Shown above are data on clinical outcomes from three standard procedures in tertiary centers, broken down into those declared by the Blue Cross Blue Shield Association to be Centers of Distinction and all other centers in the study. The data exhibit a remarkable variance in clinical outcomes, especially in the mortality rate associated with heart transplantation. These data raise two questions. First, what factors drive this high variance in clinical outcomes? Second, why do patients continue to be referred to centers with high mortality

rates, and why do private insurers pay for procedures performed in such centers?

Ignorance of these facts is likely to be the major explanation. While targeted studies can identify such variances, such data are not routinely collected, organized and publicized by insurers. Government's casual attitude towards these variances in mortality in the hospital sector stands in stark contrast to the stringent patient-safety standards government imposes on the pharmaceutical and medical device industries through the Food and Drug Administration (FDA). Why should an avoidable, premature death in a hospital be taken more lightly than a death from a problematic prescription drug or medical device? The Commission makes note that New Jersey's various health report cards indicate significant and steady improvements in the quality of care at the State's hospitals. This evidence further confirms that the availability and transparency of health care data improves quality.

<sup>170</sup>Robert M. Wachter, "The End of the Beginning: Patient Safety Five Years after 'To Err is Human,'" *Health Affairs Web Exclusive* (30 November, 2004): W4-534-45.

Finally, results from a recently published study in *The New England Journal of Medicine* suggest that, on average, children in the study received 46.5% of the indicated care<sup>171</sup>, a finding that parallels an earlier, similar study for adults published in the same journal.<sup>172</sup>

In sum, then, uneven quality of health care remains a significant feature of the American health care system, and New Jersey's health system, while improving, is not an exception to this finding. It would be puzzling indeed why patients accept this state of affairs with such equanimity – why they would opt to receive care at hospitals in which their chance of dying from low-quality care is higher than elsewhere -- were it not for the fact that patients have absolutely no idea that such quality differentials exist. Instead of transparency on so important a matter, patients have been lulled into complacency by the much-mouthed mantra that the American health system is the best in the world, a mantra actually contradicted by a growing body of evidence. As a recent cross-national study by the Commonwealth Fund concludes:

Despite having the most costly health system in the world, the United States consistently underperforms on most dimensions of performance, relative to other countries. This report—an update to two earlier editions—includes data from surveys of patients, as well as information from primary care physicians about their medical practices and views of their countries' health systems. Compared with five other nations—Australia, Canada, Germany, New Zealand, the United Kingdom—the U.S. health care system ranks last or next-to-last on five dimensions of a high performance health system: quality, access, efficiency, equity, and healthy lives. The U.S. is the only country in the study

<sup>171</sup>Rita Mangione-Smith, M.D., M.P.H., Alison H. DeCristofaro, M.P.H., Claude M. Setodji, Ph.D., Joan Keeseey, B.A., David J. Klein, M.S., John L. Adams, Ph.D., Mark A. Schuster, M.D., Ph.D., and Elizabeth A. McGlynn, Ph.D., “The Quality of Ambulatory Care Delivered to Children in the United States,” *The New England Journal of Medicine*, 272(15) (October 11, 2007): 1515-23.

<sup>172</sup>McGlynn, E.A., Asch, S.M., Adams, J., Keeseey, J. Hicks, J., DeCristofaro, A., & Kerr, E.A. *Steven M. Asch, M.D., M.P.H., Eve A. Kerr, M.D., M.P.H., Joan Keeseey, B.A., John L. Adams, Ph.D., Claude M. Setodji, Ph.D., Shaista Malik, M.D., M.P.H., and Elizabeth A. McGlynn, Ph.D.*, Quality of health care delivered to adults in the United States. *New England Journal of Medicine*, 2003; 348: 2635-45.

without universal health insurance coverage, partly accounting for its poor performance on access, equity, and health outcomes. The inclusion of physician survey data also shows the U.S. lagging in adoption of information technology and use of nurses to improve care coordination for the chronically ill.<sup>173</sup>

## B. Information on the Cost of Hospital Care

In the context of health care the word “cost” has two meanings. It could mean the *payment* the patient's insurer makes for a hospital service. A better term for it would be the “price” the insurer pays for the service. Or it could mean the cost the hospital (or doctor) incurs to deliver the treatment, that is, the cash providers pay for the inputs they use in the treatment of patients. Not much is known publicly about the payments hospitals receive from different payers for the same service. Almost nothing is known about the input costs different hospitals incur for different services or medical cases.

**Payments to Hospitals:** As was noted earlier in this report (see Chapter 6), the price hospitals receive from insurers for a standard service varies significantly from private insurer to insurer, usually in inverse proportion to the insurer's market power. That price is different again for Medicaid and different once again for Medicare. Finally, because they have virtually no market power vis a vis hospitals, uninsured patients tend to be charged the highest prices, unless they are outright charity cases. In the end, however, what low-income uninsured and non-charity patients actually pay hospitals tends to be just a fraction of the prices they were charged.

All of these varied prices for the same service have virtually no systematic relationship with the cost of providing these services, whatever they may be. Furthermore, with the exception of prices paid by Medicare and Medicaid, all prices paid hospitals from the various parties are kept a tightly guarded trade secret. Although, in principle, uninsured patients or

<sup>173</sup>Karen Davis, Ph.D., Cathy Schoen, M.S., Stephen C. Schoenbaum, M.D., M.P.H., Michelle M. Doty, Ph.D., M.P.H., Alyssa L. Holmgren, M.P.A., Jennifer L. Kriss, and Katherine K. Shea, *Mirror, Mirror on the Wall: An International Update on the Comparative Performance of American Health Care* (May 16, 2007), available at [www.cmf.org](http://www.cmf.org).

those with high deductible health insurance ought to have information on the prices hospitals might charge them, as a rule there does not exist an information base to provide that information.

As was noted in Chapter 6 (see Table 6.4) as well, there is great variation in the volume of services for which New Jersey hospitals bill Medicare for roughly similar patients. Although the medical cases represented by these patients were not 100% identical, so that differences in patients might explain some of this variation, it is hard to believe that genuine differences in acuity could have accounted for such vast differences in health-care utilization.

It was recommended in Chapter 6 that the State explore information technology capable of tracking every order entry by every affiliated physicians for every input used in the treatment of every hospital case. To be sure, the administrators of some hospitals may routinely assemble resource-use data by individual physician affiliated with the hospital, but such data are unlikely to provide adequate leverage in dealing with physicians on whose goodwill and referrals the hospital must rely for its revenue flow. After all, it is not usually the hospital patient but the referring physician who effectively is the hospital's customer. The question the Governor and State legislators must explore is whether the information should also be available to them to assess the efficiency with which a hospital is run before deciding whether or not a hospital warrants state subsidies of any sort.

**The Input-Cost of Hospital Services:** The hospital industry regularly laments that Medicare and Medicaid pay hospitals less than 100% of the full cost of treating Medicare and Medicaid patients in hospitals. It is a plausible argument, but it leaves open the question whether the “costs” to which the payers’ payment rates are compared are invariably justified. To say that Medicaid pays only about 70% of a hospital’s costs may be misleading if the hospital’s costs are 120% of a reasonable benchmark of what efficiently produced health care in hospitals should cost.

Here, too, New Jersey lacks a sophisticated information system that can routinely inform government on how a particular hospital’s costs compare to reasonable benchmark costs.

### **C. The Potential Role of State Government in Health Information Systems**

The troublesome circumstances described in the preceding subsections lead to the question of what role State government has in financing and constructing an information infrastructure designed to drive the entire health system – patients, insurers and providers alike – towards higher levels of performance. Alternatively put, the question is whether Americans can rely on the private sector to develop that infrastructure, given that sector’s undistinguished history in this regard.

So far, neither the federal nor the state governments have done much to force greater transparency on the activities of the providers of health care whose revenues depend heavily on government financing. Only in the past few years have governments begun to address this important task seriously. Although private employers and their agents (private health insurers) equally had every opportunity in the past several decades to hold the providers of health care more rigorously accountable for the cost and quality of the services paid for by private insurers, and to provide the insured public with greater transparency on the cost and quality of health care delivered by health care providers, for the most part they, too, have failed to do so and are only now making timid steps in that direction.

If the State’s government wishes to drive the State’s health system more rapidly towards high performance, in terms of both cost and quality, government probably will have to intervene rather heavily to guide the invisible and timid hand of the private market place. To illustrate, a good faith cooperative effort is currently under way by Horizon Blue Cross Blue Shield of New Jersey and the New Jersey Hospital Association to develop a so-called regional health information

organization (RHIO) that would facilitate the sharing of clinical information on patients across providers. Participation in any such effort, however, would be *voluntary* and thereby makes it difficult to develop a business model for the system from the individual hospital's perspective. Recent research on RHIOs elsewhere in the nation strongly suggest that RHIOs based on strictly voluntary efforts are prone to fail.<sup>174</sup>

### **Recommendation:**

In view of the decade-long failure of the private sector to develop such an information infrastructure – e.g., Regional Health Information Organizations (RHIOs) – the State should take a leading role in the development of such a system, financing both the research and the development efforts to establish such a system. Participation in such a system should be mandatory upon health care providers.

A strong business case for such an infrastructure could be provided if government mandated participation in the RHIO which, in turn, probably would require sustained financial support of the venture by government. That support could easily be defended on economic grounds, as a RHIO has a strong dimension of a public good. Economists make the case that, left to its own devices, the private sector will always under-supply public goods, unless their production is subsidized explicitly by government.

### **Recommendation**

To maximize its effectiveness, a future health information system should be standardized, transparent, and easily accessible. It should be managed by a public-private organization that is chartered by the State and, in view of the public-goods nature of the enterprise, supported by State funds.

<sup>174</sup>See Julia Adler-Milstein, Andrew P. McAfee, David W. Bates, and Ashish K. Jha, "The State Of Regional Health Information Organizations: Current Activities And Financing," *Health Affairs Web Exclusive*, December 11, 2007; [http://content.healthaffairs.org/cgi/search?ck=nck&andorexactfull-text=and&resourcetype=1&disp\\_type=&author1=&fulltext=RHIO&pubdate\\_year=&volume=&firstpage=.](http://content.healthaffairs.org/cgi/search?ck=nck&andorexactfull-text=and&resourcetype=1&disp_type=&author1=&fulltext=RHIO&pubdate_year=&volume=&firstpage=)

## **II. A Full-Fledged 21st Century Health Information System**

A full-fledged, state-of-the art health-care information system already being developed in several parts of this country and, sometimes even more rapidly, in other nations would serve the following distinct objectives.

1. It would allow physicians and other providers of care throughout the state carefully authorized access to each patient's complete medical record.
2. It would endow patients with a personal electronic health record that would help them better to manage their health and their use of health care.
3. It would offer the providers of health care and those who pay for it (mainly third-party payers) adequate information to facilitate the business transactions surrounding health care smoothly and more cost-effectively than is now the case.
4. It would routinely provide data required especially by government (which pays for close to 50% of all health care in the U.S.) and communities to hold the providers of health care accountable for their use of real health care resources in the treatment of patients.
5. In particular, it would yield the data to hold physicians routinely accountable for their use of their own and their affiliated hospital's real resources in the treatment of patients. Thus one could explore, for example, the huge variations in resource-use and hold the individual physicians driving these variances formally accountable for them.

### **A. Different Records in a Health Information System**

It would not make sense to develop one giant electronic record that could serve all of these diverse objectives at once. Instead, there should be a common master file – sometimes called the “spine” – that would contain data used in raw form or transformed by several or all of a set of electronic records customized and enriched with yet other data to serve the narrower objectives listed above. These various electronic records may be described as follows.

**Electronic Health Record (EHR):** An electronic record is any combination of text, graphics, data, audio, pictorial, or other information representation in digital form that is created, modified, maintained, archived, retrieved, or distributed by a computer system. An EHR is a larger concept in that the electronic information is more than the clinical information; it includes demographic information and sometimes payment codes, such as IDC and CPT codes. The electronic information is shared within a larger organization or with a second outside health care entity and follows federally recognized standards such as HL7 and X12. EHR can and should be certified by the CCHIT. The master “spine” might consist of such EHRs.

**Electronic Medical Record (EMR):** The purpose of the EMR is designed to be an electronic interface among clinicians. It would allow any physician authorized to do so by the patient or the patient’s guardian to access that patient’s full medical record, or authorized parts of it, which would include a medical history, the patient’s current drug regimen, all tests previously done and observations recorded by other physicians. The EMR would be kept in the clinical language understood by clinicians. This objective could be accomplished either by a smart card carried by the patient or by what is known as the VISA system, that is, a card carried by patients that permits authorized access to a central storage location for the patient’s file. The EMR would meet the first of the objectives listed above.

**Personal Electronic Health Record (PEHR):** The second objective listed above is met in various locations around the world by a PEHR, which is a multipurpose record written in language lay people can understand and allowing patients to see their most recent test results, graphical or tabular histories of test scores for particular metrics (e.g., blood pressure), their current and past prescription-drug regimen and so on. There would be electronic links from test results to explanations of these results and further links to the relevant literature, perhaps ordered by level of difficulty. Patients would also find on this record relevant treatment options for particular medical conditions, and guidance for proper health maintenance, including nutrition. Ideally, such a file should also provide links to reliable information on sundry dimensions of the quality

of care rendered by individual providers of health care and, to the extent that it is relevant to patients, information on their share of the cost for procuring health care from particular providers of care. Finally, patients could make appointments with physicians via this record, or communicate directly with individual physicians.

All of these desiderata may appear as too much of a load for a PEHR to carry. The fact is, however, that such records are already in use here and abroad and are spreading rapidly. Here it must be noted that the establishment and maintenance of a PEHR requires a sponsor who both finances and manages it. One alternative is to lodge that responsibility with third-party payers, who could recover their costs through premiums or user fees levied on the insured. Another alternative would be to lodge that responsibility with the patient’s “medical home,” that is, the patient’s primary-care physician, who would be explicitly paid for that service by third-party payers (or strictly by government). The model of the “medical home,” now still mainly a concept on the drawing board, has captured the imagination of health policy makers around the world.

One could imagine entrepreneurial companies to establish medical homes, replete with sizeable computer systems and staff to support it, should physicians in their medical practices shun this task. These entrepreneurial companies could contract with both private and public insurance systems.

The other objectives listed above would similarly be met by customized electronic records all of which, however, would share a common, standard nomenclature, to permit easy transmission and comparability of the data. History suggests that the development and adoption of such a nomenclature would require the guiding hand of government, along with at least some public financing.

Of particular note here would be a data system tailored to meet the 5<sup>th</sup> objective listed above, namely, a system capable of tracking the hospital resource use of individual, affiliated physicians by medical case and by input, to facilitate holding physicians accountable for the health-care costs they authorize over their signature.

## B. The Financing of a Health Information System

As noted in passing earlier, a state's or nation's health information system has dimensions of a public good. In economic analysis a public good is one whose consumption or use by one person does not detract from any other person's use of that good. A second, less important dimension of a pure public good is that it is non-excludable, which means that everyone can enjoy its use.<sup>175</sup>

The information produced by scientific research is a pure public good – e.g., Einstein's famous equation  $E = MC^2$  or the Pythagorean theorem – is a pure public good, as is the security provided by national defense and homeland security. Clearly, a common database, once it is established, has this feature. Economic theory shows that such goods would be under produced by the private sector unless the production were collectively financed, typically by mandatory levies such as taxes.

Even goods that appear basically private consumption goods exhibit so-called “positive ties” that represent public-good dimensions. Telephone networks, for example, are such goods, because the value of a privately owned telephone increases with the number of other privately owned phones to which each telephone connects. When one person buys a telephone, all other telephone owners benefit. Economic theory suggests that the production or purchase of such goods should receive public subsidies as well if society wishes them to be produced in sufficient quantity.

The upshot of these reflections is that, because of its connectedness across the health system, a healthcare information infrastructure has dimensions of a public good and thus ought to be supported with public subsidies. The development and maintenance of the system's common data base (its “spine”) in particular should be heavily government funded, even if the actual development and maintenance is delegated to a private entity. Early experiences with regional health information systems have demonstrated the importance

of sustained public sector support – many systems elsewhere have failed by relying on private sector funding which often is inadequate over the long run.<sup>176</sup> Furthermore, to reap the full benefit of a health information infrastructure, participation in it by individual providers of health care should be mandatory.

## C. Progress to Date in New Jersey

Legislation has been proposed that would create a central repository under the authority of the Department of Banking and Insurance. Under the proposal the initial source data for populating the repository would be the electronic claims data processed and maintained by health insurers, including the New Jersey Medicaid program.

In addition to that information, the proposed repository could also be populated with health data maintained by State agencies including the following:

- NJ Hospital Discharges (UB-92)
- Cardiac Utilization
- Quality Reporting
- Patient Safety Reporting
- Cancer Registry
- Childhood Immunization Health Registries
- Medicaid/NJ FamilyCare Claims
- Annual Hospital Cost Reports
- Annual Hospital Financial Statements
- Unaudited Quarterly Financial and Utilization Reports

As referenced earlier, the New Jersey Hospital Association and New Jersey Blue Cross/Blue Shield formed the EMR/EHR taskforce to develop Regional Health Information Organizations (RHIOs) around the state. Data collected through these organizations could also be used to populate the repository.

<sup>175</sup>Sometimes an intrinsically public good is artificially made excludable through law – e.g., by patent protection.

<sup>176</sup>Adler-Milstein, J., McAfee, A.P., Bates, D.W., and Jha, A.K. The state of regional health information organizations: current activities and financing. *Health Affairs*, 2008; 27(1): w60-w69.

**Recommendation**

Developing and sustaining a health information system is a very difficult task, but one that holds great potential to improve health system performance. Therefore, the Commission recommends that the State should form a commission charged with developing the framework and policies around the development of a regional health information system, drawing where appropriate on similar efforts elsewhere in the United States and abroad. Such a commission needs to engage many key stakeholders to overcome these challenges.

New Jersey's health care system and the population it serves would greatly benefit from the development of a clearinghouse for electronic health data that can be accessed by all interested parties. In essence, it is envisioned that the clearinghouse would function as a spine from which users would be able to extract and utilize data to suit their particular needs. While it is anticipated the development of such a system will take several years and occur in incremental steps, there are basic guiding principles that must be followed.

1. Public/Private Partnership – the sensitivity of the data mandates that security is paramount. Therefore the oversight and control must ultimately reside with government but the operation and output should include and reflect private sector concerns.
2. Standardization – As with any system the consistency of the terminology is critical.
3. Transparency – the system's basic functionality and data elements must be available at little to no cost and be understood by the general public.
4. Routine Outcome/Health Status Reporting – there should be regular periodic publications that summarize and report key utilization and health indicators.

5. Information already available in payer data warehouses must be used to begin populating the database with historical information that already exists.
6. Hospitals and individual practitioners must have an easy-to-use, one stop repository that can be accessed securely over the internet without forcing the adoption of another unique hardware/software configuration.
7. Laboratories, imaging and radiological facilities should file test results, reports and digitized images with the EHR Custodian for use by providers.
8. Pharmacy Benefit Managers should be required to supply filed prescription information with the EHR Custodian. Steps should be taken to remind consumers to follow recommended medication usage especially in chronic disease management.
9. Durable Medical Equipment Providers and other health care support providers should file reports with the EHR Custodian.

In view of the decade-long failure, to this day, of the private sector to develop such an information infrastructure – e.g., Regional Health Information Organizations (RHIOs) – the State should take a leading role in the development of such a system, financing both the research and the development efforts to establish such a system.

To maximize its effectiveness, a future health information system should be standardized, transparent, and easily accessible. It should be managed by a public-private organization that is chartered by the State and, in view of the public-goods nature of the enterprise, supported by State funds.

### III. Conclusion

Transparency is a critical step toward improving the performance and accountability of the health care system to “lift the fog” that is currently hindering progress toward high quality, cost-effective care. An information infrastructure is necessary to address the unjustified variances in clinical practice across the state and the nation as a whole. Government must play

an important role in the creation of a 21st Century health information system. The characteristics of such a system resemble that of a public good, which firmly calls for a government role. The absence of such a role will lead to chronic underinvestment in this important area and a failure to maximize value from the health care system.





