

## Health Data in a Banana Republic

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The following are thoughts on the status of Wisconsin as a progressive health data democracy and, therefore, the meaningfulness of the current administration and provider sponsored “colloquiums” on health data. These thoughts do not necessarily reflect the views of any other individual or institution. This is a non-partisan essay on who should rule health data in a progressive democracy.

Whenever the words “public-private partnership” are used it is usually a euphemism that the “public” has already been defeated or has given up the field to the “private”. The partnership is no more than the names of both partners on the door for appearance sake; but the power and assets all belong to one. In short order it will be clear that these partnerships are actually “Private-Private”. Yet in a progressive society the appropriate partnership is “public-public” where the long standing and politically neutral government agency has a partnership with the people. The partnership is a buffer between the citizen consumers and the private sellers. In a Progressive democracy those who own health care would not be in political control of it or its data and the use of that data.

This is especially true in health data as the basic rule of social epidemiology 101 is that:

1. Politicians + Professors + Providers {not equal to } Public.

One knows one is in a progressive democracy if:

2. Politicians + Professors + Providers < Public.

One knows one is in a Banana Republic if:

3. Politicians + Professors + Providers > Public.

In Wisconsin, the progressive movement was bipartisan. It was a turn of the century movement encompassing both republicans and democratic populists allies. It drew on a longer traditional going back to territorial days in terms of focusing on the protection of consumers:

- 1838 Honest Weights and Measures
- 1858 Restrictions on “Dishonest Itinerant Peddlers”
- 1889 Safefood and Accurate Labeling
- 1903 State Lab of Hygiene
- 1905 State Health Report
- 1918 Outlaw Deceptive Advertising
- 1921 Investigation of Unfair Business Practices

- 1929 Consumer Protection Agency Created

It was captured by the democrats in the depression, but in Wisconsin eventually embraced by moderates in both parties after WWII. In the last forty years it has been a profound influence on Wisconsin government, until recently with the rise of neo-conservative and neo-liberal office seekers. The protection of the consumer started in earnest at the turn of the century and has continued throughout Wisconsin's long progressive tradition. Only in recent years has the regulatory roll back started.

Similarly, the modern era public sector health data infrastructure of Wisconsin was built during the recent republican administration with strong democratic legislative support and in opposition to the provider associations. Its deconstruction is just the obverse, as is a Banana Republic to a progressive democracy.

### **I. What Does How Health Data is Handled Have to Do with a Banana Republic?**

Millions of words have been generated on the issues of the role, type, quality, technology, funding, governance and the use of health data. This has been predominantly about health care data and only secondarily about public health data. Unfortunately, not as much ink as lobbying words and dollars have been spilled in Wisconsin. However, the sparse literature at the state level or in the volumes of the United State's publications are mostly silent on the philosophical relationship between a society's approach to health data and a nation's political approach to democracy. This is a strange omission in that society's long term approach to health care and health data usually provides an interesting and sometimes reflective mirror of the health of its political democracy's depth and range for all levels of society. Despite the fact that the origins of broad health care access to the majority of citizens in many nations has been tied to imperial adventures, once established over time, the substance of the progressive nature of the political democracy of those nations and their view of both access to health and health care data begin to parallel.

The reason for focusing on the concept of a health data progressive democracy is that if this is not the underlying purpose of such public "data colloquiums or symposiums" in a democracy, what is? A public symposium in a progressive democracy assumes the public is controlling the discussion and the resolution of the issue. Later in the essay, the more explicit definition of a progressive democracy will be discussed and its implications for health data; but it is sufficient here to note the measure is whether the demand side: buyers, consumers and the government agencies representing those in the public are in charge. Does the public rule or not rule? The other title given somewhat inaccurately to the progressive movement is "Populism". Yet as a concept it captures what a health data progressive democracy should be about. If the purpose of a health data colloquium or symposium is truly public policy for the benefit of the public, then the end game is the creation of a health data progressive democracy in Wisconsin, If this is not the premise underlying the meeting then this means the topic is only making a more clever health data

Banana Republic, where the supply side continues to rule for the benefit of the few and to keep knowledge and power away from the populist many.

There is no reason for having a public discussion concerning health data issues just within the supply side of the business context of health care. Public discussions in a Banana Republic are merely for show. If this is primarily about how health care providers (private or public) can carry out their data business, for their own interests, or selling it to buyers or handling information exchange with the government, why a public symposium? One does not need a public symposium for that; but by-invitation only golf tournaments at private estates.

If it is to only provide suppliers and sellers with a more noble title to what they are doing or to provide the cover of academic and political sponsorship, why bother? This is, especially true, if the demand side is only nominally there and government is just a friendly bystander- waiting on the beneficence or voluntary agreement of the supply side. Clinics, hospitals, claims processors, financial intermediaries, university health complexes, government direct care health programs and insurance companies have both the tools (technically, such as new portal technology and legally, such as HIPAA) as well as the profit motive and/or self interest to be developing and implementing strategies for health data exchange as a business transaction.

This distortion of the fundamental purpose of public policy in the area of health data is nothing new. Behind most health data “public policy” in recent years, outside of their public relations spin, there is little to do with collective public interests; but everything to do private interests and with supply side net revenue and power. Whether it is recent federal legislation and initiatives concerning data exchanges or Wisconsin Chapter 153 changes or the new rage of RHIOS, Data Networks, Quality Cooperatives and Consortiums much of the motivation is very simple. They are substantively driven by classic supply-side economic and political power incentives. The fact that they are endorsed by current state legislators and executive branch merely reflects the supply side dominance in neo conservative and neo-liberal politics; not the progressive democratic tradition that made Wisconsin, the political model for the nation.

The federal “leadership” in health care data and the automation of medical records is presented as “cost savings” with Presidential predictions of a 25% reduction in health care costs. One can view that in light of recent Presidential predictions and the reality of any cost savings being passed on to consumers vs. profit and expansion; but the political reality is this is counterpoint to real health care reform, such as single payer universal health care. In a progressive democracy the purpose of public policy on health data is not to make the supply side more powerful or protected: Aurora more expansive or WPS more profitable or WHA less paranoid. That is what capitalism, the “ownership” society and the pursuit of “fifthly lucra”, as the Freudians define it, is all about. However, the fact that the participants at Wisconsin health data colloquiums or symposiums look like natural foursomes of the affluent medical and health care business elite with an admiring gallery of government and academic hanger-ons makes it even more transparent.

## **A. Principles of a Progressive Health Data Democracy:**

The definition and characteristics of a health data democracy in a progressive society are fairly straight forward. They have nothing to do with making the suppliers of health care in the nation with the highest international: per capita and percent of GNP health costs, professional medical fees, health insurance premiums, HMO profits, hospital executive salaries and total gross costs for health care any more bloated. The focus on a health data progressive democracy is on the consumer and buyer side of health care and the citizen side of public health for the collective community. From a consumer/buyer perspective the goal is to lower all of those above indicators.

In a progressive democracy health data policy would focus on different things: consumer and buyer access to health data, more effective public regulation over health care, improved public health outcomes and infrastructure, consumer/buyer protection, better quality indicators for more forceful buyer intervention, maximizing access, reductions in unit costs to be reflected in lower prices, reduction in unnecessary utilization and lower reimbursement....

The history of progressive democracies always start within a class context. Rather than a European anti-capitalist critique of the struggle between capital and labor, the class war for American Progressives has always been between producers and consumers across the market and between big and little on both sides of the market. However, this has usually been within the context of capitalism. This historic progressive focus is in opposition not to capitalism or the market; but to those who control and dominate the supply side of the economy and have power over the buyer side. The inherent focus of progressive support is the consumer. This is true concerning any product, including health care and health data.

The below progressive health data principles are derived from understanding on what side of the market the majority of citizens stand, which should also be the side of democracy and , therefore, the side on which the political structure in a true democracy would stand. The fact that current government policies favor the opposite side, the supply side, is one of the miracles of current Wisconsin and American democracy.

- As all health data reflect the health conditions and status of the health of the entire society whose betterment and protection is a collective right, then all health data are social assets and not a private commodity. Therefore, in a progressive health data democracy:
  - *All health care and public health data (across all providers, populations, institutions, payers and services) are a public good.*
  - *The only entity that can represent all consumers and all citizens is the government, therefore, health data is managed and controlled as a collective asset by the government on behalf of all citizens.*

- *Its collection is a mandated civic requirement of all entities engaged in the provision of health care and all aspects of that data are provided to the state.*
- *The collection, storage, analysis, and dissemination of that data and the public infrastructure of those data functions data are funded through general tax revenues.*
- *It can be used (shared, linked, merged and analyzed) by all levels of government without restriction for setting any public policy in terms of licensure and regulation, rate setting, health planning, quality of care determination...*
- *Government can disseminate and publish that information for the benefit of citizens and consumers without restrictions as long as there is no public disclosure of individual consumer's identifiable health information.*
- *The data itself and not just stripped de-identified data can be used by any public health entity for epidemiology, follow back or any other population based health need and for any allied academic research purposes that comply with data handling agreements authorized by the state.*
- *It can be accessed freely, continuously and used without restrictions by all consumers and buyers: individuals and institutions in society (outside of government) within only the constraint of the public data set not containing identification of specific individual's health care status or information.*
- *No elite or caste of secular priests can require of the public that their access and use of the data must be justified to the officials, as worthy or that this caste can tell them what this data means and what it can and can not be used for. In a health data democracy there is no caste of data priests with any public power.*
- *The consumer of health data is sovereign and the protection of their interests is the first business of government.*

In fact, in the appropriate political sense a “Progressive Health Data” public colloquium or symposium would have no market dominating health care supply side representation. Getting information on food product content and processes for the reform of the meat packing industry in 1900 did not happen at plush conference centers across from the corporate offices of Hormel. 70% of the participants at those reform meetings did not consist of slaughter house owners or “pork bellies” commodity brokers or lawyers. There might be small scale hog farmers, corner butchers and the country corner meat packer represented along with housewives, but not Armor. At a true public symposium to develop a progressive health data democracy would be consumer groups, health care reform advocates, buyer coalitions, individual citizens, unions, civil servants involved in rate setting, health planning and regulation, public health officials, researchers (not affiliated with provider groups) and progressive politicians not behold to supply side influence. They would more likely meet in a union hall for a bowling event, then on the first tee.

The results would not be a public show of participation that meant nothing, agreements to meet again, sanctioning the status quo until more research can be done or voluntary agreement for potential cooperation...Nor would it be cover for government to abandon their rightful role based on selected “public feedback.” The results would be proposed legislation and regulation to move the state forward to a health data democracy, independent of what the “Canned Meat Kings” wanted.

### **1. Public Health Data and the Buyer-side of the Market**

A progressive health data democracy would not, however, be just an unstudied hymn to buyers. Just as the sellers in capitalist economy have a set of socially perverse institutional behaviors, that require collective regulation; so do buyers in a “free” market context. Does one have the right to smoke in public or are the recent Italian regulations that prohibit it and which are based on public health data more appropriate? Whether it is junk food, unsafe autos, environmentally destructive products uncritical support of consumer rights is equally folly to uncritical support of seller rights. If buyers want what ever they want or the ads tell them to want, as much as they can get, as fast as they can get it, as cheap as they can get it and at their definition of what is “healthy”, public health of the community as a whole is at risk. Wisconsin did not rank first in binge drinking and obesity for nothing. Current consumers also want the unlimited right to bring the product back for a refund and/or sue, if they did not get what they want or thought they would get. More socially perverse is that the buyers want someone else (government / firm / family / community) to pay for the consequences of their irresponsible health or environmental consumer behavior. Whether it is tobacco, gasoline inefficient cars, Twinkies, botox or the cornucopia of malls available in Banana Republics conspicuous consumption and destructive egoism abound on the buyer side of the market.

Without better public health data and regulations and public messages based on that information consumers will not make wiser choices. The same is true of health care data and health care regulations based on that data. Without these tools consumers and buyers will not improve their behavior as health care consumers and make wiser and better decisions. If all they know about a provider is pictures of smiling doctors and nurses and children running through fields with puppies back-grounded against health system logo across the morning sky, they will never be independent consumers. The arrogant affront is that they, the people, do not need unrestricted access to health care data because they can never be intelligent health care consumers. Because of the complexity of the issue they need to be professional guided by providers to correct conclusions. This makes health care the last bastion of supply side hubris.

One could not imagine after 1930 having meat packing plant executives telling consumers they do not understand science enough to make sense of information about bacteria in their hamburger, therefore, they have no right to know. Now in the 21<sup>st</sup> century when DNA typing of Ecoli-157 can be done immediately, recalls happen within hours and suppliers are humble in their public statements. The auto industry gave that stance of arrogance up with Ralph Nader in the 1960's. The tobacco industry folded in

the 1990's. If that is true why still do physicians and health care administrators believe the public would only mis-understand health data and that the provider community has to select what information is available and what it means? Only in health care in a Banana Republic would anyone assume they have any political right to even suggest such paternalism.

The buyer side is where public health and population based data comes into a progressive health data democracy. From public health the collective data on population health status and prevention research should be a powerful social weapon and the focus of government action in the market. Public health is public education and behavior change. This is different, but in some form an equally difficult task as what is needed on the supply side. On the buyer side is the cultural barrier of defining collective good as something greater than the aggregate of the immediate desires of each individual consumer. The control of unnecessary use of health care resources, the change of horrid and dangerous personal health behavior, the prohibition of environmental destruction, the reversal of public acceptance of snake oil health cures and absurd expectations on results of health care, changing life styles that kill and limiting the ready access to products of risk at low prices. . . . .are all buyer side problems. They are inherently public health problems. They require an equal level of collective moderation through regulation, education, product licensing, product taxes and most importantly a strong tax supported public sector public health infrastructure at the local, state and federal level. This public health infrastructure needs to be funded at more than 1% of the total health care dollar and for doing something other than being a camp follower in the "war" on terrorism.

These policies should be shaped by public health data and population health research. Yet in the current environment where does the need for government intervention rest, where are health data dollars needed and what is happening to the public sector infrastructure of public health? The answer is not much; but in a Banana Republic not much in these areas ever happens. There is no strong public health infrastructure to move the buyer side of the market towards more progressive policies and practices. In a Banana Republic the pressure is to allow one to get anything they want as long as its does not offend cultural taboos, and they have the money. Any regulation or restriction is fought as oppressive government interfering with the "rights" of the people. Public health is only to keep cholera confined to the barrio. Nor in a banana republic is health care data, when it exists, used to shape and constrain supply side power in the market.

If this state were a progressive health data democracy there would also have to be a follow up to a health care data colloquium with a public health data symposium. A public health buyer side symposium on population health data would be equally needed. There community groups, consumer advocacy groups, environmental organizations, health care buyers and government would propose equally strong laws, regulations and requirements. Just as provider political pressure is huge and greatly impacts politicians to protect those perspectives in the name of the people, this progressive public health agenda, would be very unpopular in certain areas. No one wants to be told to stop smoking, yet a \$5.00 tax per pack or licensing tobacco as a "drug" is even less popular. Public health data leads to harsh parallel conclusions about the need for public health infrastructure strengthened

with public tax dollars; better safety regulations; more mandatory requirements in such areas as vaccination, child care, smoking restrictions; the use of public health sin taxes on alcohol, for example; tougher regulation on what people could access that only adds to their health problems; more costly product protection requirements; more meaningful environmental restrictions and rationing to prevent unnecessary over utilization of health care.....

When in a Banana Republic has one heard politicians campaigning on these public health themes except the undocumented mantra of the evils of all drugs and the benefits of just abstinence in all circumstances. Yet in a progressive democracy there would be public health platforms and population health data would be used in all these efforts.

## **2. Information Technology in a Progressive Health Data Democracy**

There is one more characteristic of a health data progressive democracy: it is in tune with the “harsh logic at the core of this technology” and its future. It uses technology to move towards equalitarian democracy, not away from it. If the future of health data management is electronic collection, storage, analysis and exchange; the future of information is the world web as a collective asset. In the internet world information is more and more shared without restriction and it is free. Whether it is the content of university libraries, NIH and NASA research results, demography and census data, agricultural and business statistics, the hundred best rib joints in America or 10,000 WEB sites on tap dancing: it is all out there as a free public good. From Google on down to Napster the future of data and information is to give it away free and have it available to all world wide on the WEB. Commerce is detached from pure information and is only reconnected at the point of sale of commodities and services –not data. The search is free and the ads are on the screen borders on the far right. If you want to buy a product, click here. The more people have free information and the creativity to do with it as they will, the smarter is society. If users can access information without the suppliers of that information knowing who is doing what and for what purpose- that is the engine of progress in an information democracy. The next generation that is growing up on the web will expect information to be 24x7 available and free. Only in a Banana Republic is the primary use of the Web e-commerce.

Confidentiality of health care information is an interesting sacred concept as currently at the individual patient level that data electronically moves from clinic to clinic, insurance company to claims processor, clinic to government....all under HIPAA business partner agreements. Therefore, confidentiality is a relative term. Free health care data for the public does not require a violation of that confidentiality. This can be protected electronically through de-identification of the data put out for public access. However, providers have used those issues of confidentiality to block health data sharing with the public; yet the web is used on the supply side to generate the life blood of health care: prompt reimbursement. If the data is good enough to be commercially shared to generate payment, why is it not good enough to be shared with the ultimate payers- the public. No one is asking that payment is slowed down until the commercial data exchanges can be shown to be 150% secure.

In this web era other producers of goods and services use the web to know for the same consumers everything they ever bought in a store, what they ever looked at on every web site they clicked on, what they ever paid for on a credit card, where ever any bank bounced their check and anytime they went into court. There is a data company in the South that does 1 billion data updates a day on 176 million consumers in their database. They sell this data to anyone with money to buy. HIPAA does not apply to these data, even though many transactions reflect things of great personal meaning. The point of these comments is not to urge publicly accessing identifiable personal health information; but that the ideological jealousy of privacy for the public on the health buyer side has its strongest advocates from the wealth on the supply side. It gives cover and justification to also protect their identity as providers. This is while their corporate commercial counterparts have market information on everyone. It is ironic that those who cry most loudly to allow providers to keep health information sacred are also the loudest advocates of free market capitalism, whose goal is to know everything one can know about the consumers.

Controlling data and information is just 21<sup>st</sup> century censorship, like removing Tom Sawyer from the local library. Material is censored because those who control or would like to control society do not like something or do not want others to like or know something. The web is not censored. The web is a perfect progressive data democracy. The concept of health care information as a private commodity and asset to be controlled, managed and restricted as well as privately sold or distributed is a look back to the last century. It might be going too far to define down loaders as the revolutionaries of the future; but the concept of Tom Paine is alive and well with the down loaders of the world.

## **B. Principles of a Health Care Data Banana Republic:**

A health data “Banana Republic” is where health data and to a lesser degree public health information are a private commodity- like canned meat.

- Health data is a proprietary commodity under the control of private organizations and individuals or groups of those entities.
- Government rhetoric and actions are controlled by private lobbying for the interests of the few over the many.
- Provider and payer institutions control use and access to that data both directly and indirectly for buyers, government, researchers, media through exclusive contracts, data use agreements and pricing.
- The producers and suppliers of goods and services rule and the individual consumers are secondary
- Governmental access and use is by exception and fragment authorized via specific legislation for each type of data or by government’s payer status rather than as an unfettered political right of the representative institution of the people.
- Public access to even non-identifiable information is a limited and restricted privilege, where access is ultimately defined and constrained by the providers through business practices and political influence.

- Public access requires the purchase of data in a non competitive health data market.
- The analysis and use of that data are restricted to a sanctioned hierarchy of the worthy as defined by the provider community which is in-turn sanctioned and enforced by the government Junta.
- The use of that data in terms of real politics is based not on the political credo of the protection of citizen consumer personal identity; but more importantly provider identity and privilege protection.

### **1. Who is the Supply Side of the Health Data Market?**

What is the supply side in the health data arena is complex. (See table 1.0 below) There are the wholesalers of health data, who produce and sell as well as use their own data. There are the retailers of health data, who buy and sell other's data. These are all supply side players. There also are the classic consumers/buyers of health care data who buy and/or acquire the data of others and use it themselves or share it with others to use. More interesting are the larger health care entities that are on both the supply side and demand side of the market at the same time. They produce data, sell data, buy or acquire the data of others and use both theirs and other entities data in very high volume. They are the "datagopolists" for whom these "data exchange" ventures are most beneficial. The participation of these entities in national "exchanges" or such organizations as the Wisconsin Health Information Exchange (WHIE) is most productive. Despite being both buyers and sellers; the big players can be most appropriately placed on the supply side as their core business is as the entity that generates health care data. Interestingly enough these are not just the large health systems; some government entities that directly provide health services and many large universities where health care enterprise weighs equally with scholarship, are also datagopolists.

Firm/entity	Supply Side		Demand Side		Function
	Produce	Sell/ Share	Buy/ Acquire	Use	
A	X				Wholesalers
B	X			X	
C	X	X			
D	X	X		X	
E		X	X		Retailers
F		X	X	X	
G			X		Consumers (general public)
H			X	X	
I				X	
J	X	X	X	X	Datagopolists: Health systems, government, Medical IHEs.

### Health Data Market

Table 1

This is why the current joint sponsorship of these symposiums is so perfect. It also faces a fundamental question, whose answer ends the debate about democracy or a banana Republic. If government, large health care systems and universities are already “datagopolises”, where should public policy put the responsibility for the collection, repository, management and societal access to this information? The answer is not a technical one; but a political one.

If a society is a banana republic, it goes to the “private sector.”

If the society is a progressive democracy, it goes to the government.

If the society is a banana republic masquerading as a progressive democracy, it goes to the university or some public health institute shell – out of the public sector.

Independent of the virtue of individuals on the supply side: providers, health care technology/research, government service provision programs, fiscal intermediaries (claims processing/insurance) and allied industries all embrace the reality of organizational supply side behavior. From Albert Schweitzer (who did not want to be told by anyone how to practice tropical medicine) to Mother Theresa (a relentless and fierce fund raiser) to rural Wisconsin FQHC’s, that also happen to have 300+ physicians, the behavior of the supply side has not changed since Adam or Adam Smith. Organizational behavior on the supply side behavior focuses on:

- (1) maximizing net revenue
- (2) expanding market share

- (3) limiting external intrusion on enterprise operational management (i.e. lessen government regulation, public oversight or just get a friendly Board of directors.)
- (4) growing in size as an organization
- (5) limiting competition
- (6) improving public image and product “blue sky”
- (7) limit legal liability and risk

From a supply side perspective this is how capitalism works, independent of the field of endeavor, the for-profit or not-for-profit shell of the organization, the personal virtue of individuals in the business or what the “mission” statement on the marble wall says . Health data improvements within the supply side primarily happen because they help supply side business. Similarly, those required government health data programs that the suppliers feel they do not want or benefit from (such as Federal Home Health reporting requirements or POVVD) are viewed as bad for supply side business and, therefore, for the universe. Left to themselves suppliers are more than capable of coming up with data innovations that benefit themselves. Health data changes for them are good if they facilitate the reduction in health data transaction costs. Faster electronic claims makes both insurance and providers bottom line fatter. Medical records data sharing between providers also reduces both operating costs and the opportunity costs of medical errors. The research implications of these data pools look good for pharmacy clinical studies and NIH grants to medical schools. Selective quality indicators make great advertisement; just as selective silence can do no harm. Better health data technology allows insurance companies, private and public payers and providers to do business faster at a lower per record cost and for claims warehouses and software/hardware sales people to dip their beaks.

In a fundamentally non-price competitive industry not a nickel of these cost savings will be passed along to consumers nor will the public sector or consumers have unlimited access or unfettered use of this supply side data. Therefore, what is the public policy issue involved in health data symposiums that are supply side dominated? They merely institutionalize the already implicit provider control of data as to what gets out, who gets it and under what terms it can be used. Other than political correctness and making the sponsors feel important, there is no need for supply side initiators of these events to hold any public symposiums. It is rather in their best interest not to, as any public involvement is a minor hazard in a less than perfectly scripted agenda with a less than perfectly pick participants.

## **2. Why Wisconsin is Headed Towards a Health Data Banana Republic?**

Knowing whether Wisconsin is currently moving away from a health data progressive democracy to a health data Banana Republic does not require much analysis, much less a symposium.

- POVVD data was given up in the budget and then removed to be put back on the legislative plate again.

- No effort was made to actively fix the program by making it a comprehensive outpatient data set from all providers and for all data, instead symposiums are held to ease its death or out sourcing with “community input.”.
- DHFS delayed both expansion of the program and release of POVD data for 18 months and refused for nearly that same period of time to allow the investment of funds in that program, although both actions were perfectly legal and funded.
- Hospital inpatient, Hospital financial and utilization data, FSAC data and emergency room data were politically handed over to WHA based on a provider favorable law, contract and data use agreement that has restricted use of that data.
- Hospital Outpatient Data will also be a WHA monopoly and a “gift” to the state, independent of resources to do anything with it.
- Bureau of Health Information lost over a score of employees to WHA take over and budget cuts and much of the fiscal support for its IT infrastructure to support public use of that data.
- Public Health Information Network (PHIN) is still entirely dependent on federal bioterrorism funds that are declining, when it should be a state level dual use priority, yet no explicit system investment has been made with state funds.
- The political visibility of DHFS as a government entity in terms of a health care data repository, analysis center and dominant dissemination point is declining as their staff are slashed.
- Wisconsin, unlike 19 other states, does not share its MA health care data routinely and freely with the public health programs outside of MA, despite them being in the same state agency.
- The epidemiological resources and staff of DHFS for public health information are still dependent on federal funding, which in areas, such as BT, is declining.
- The EMS information system has not been funded and the bureau devoted to them has been dissolved.
- Data systems for health regulation, such as the Lead Registry, have been neglected and in the process of being discarded.
- Bureau of Labor Statistics programs (DWD) are cut a drift through budget cuts and must migrate to University to survive as state functions.
- Division of Public Health has seen and is proposed (over the last and proposed biennia) to have nearly a 20% staff reduction, that is the infrastructure of doing anything with the data, even if part of it is “free” from WHA.
- Justification for health care data has been turned to a more innocuous public health only purpose in the support of the state health plan rather than rate setting, regulation, health planning and consumer safety –even though not one new state tax dollar has been invested in the state health plan.

The list goes on and on; but there is no evidence that the wave of health care data moving Wisconsin towards a progressive democracy is anything but going out.

### **C. The Problems With a Health Data Banana Republic?**

One usually only has one problem with a Banana Republic: when one is not inside the Junta. However, by definition it is not much of a Banana Republic if the vast majority of

citizen are not outside. That is the whole point – keep the good for the few because it means more good for the few. The difficulty is that the public good of health data only happens when the public has access to it. In having the supply side monopolize or control it, a number of unfortunate events happen that are not optimal for any collective society. Interestingly enough these same problems come back to hurt even members of the Junta in the long run.

### **1. In a Banana Republic Only Partial Data is Partially Available.**

If one imposes any price on the data some with the least economic means are excluded from acquisition. Equally destructive is that in a “free” market all exchanges are monetary and voluntary. On the supply side only fragments of data will be available because of market differentiation.<sup>1</sup> Unless the set of providers is universal and that of buyers is universal and all agree on a price- only some data will be exchanged and available.

However, if government was to play the role of aggregate buyer for all, the assumption would be that part of all would be needed by someone at some time, so making all available to all free at all times is the optimal. That is not going to happen in a banana republic.

### **2. Only a small set of market consumers can engage in exchange.**

Far from being the universal set of all buyers and all users, the problem becomes that even if every supplier in a health market made all of their information commercially available, but had to collect funds from a specific set of consumers of data to cover the cost of specific data, the market transaction costs would be both huge and the data available small. The problem is market imperfection.<sup>2</sup>

However, if government collected a tax from all and paid all providers for all information at the cost of its production and provided it free to all in society (who paid for it via taxes) the market imperfection of dealing with a collective good would be eliminated and the cost to society would be no more than a perfect market would extract. But that is never going to happen in a banana republic.

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<sup>1</sup> If the *i*th producer of health data must individually exchange with the *j*th consumer of data in a market transaction for the mutually defined and exchanged *k*th piece of data, the universal set of all data is not available. It is only the small set of the intersections of these market partners that will identify available data.

<sup>2</sup> The *i*th provider can recover revenue for the *k*th data item from only the *j*th buyer in the market at any given moment, who is willing to buy it at the seller’s price. However, because of market imperfections the *i*th provider can only collect from a sub set of all potential buyers that might or might be able to generate enough sales at that price to recover the entire costs of the data. Therefore, the *k*th item might not be made available to anyone and, therefore, no one. Similarly, the *j*th buyer would be willing to pay for a wide range of information, including the *k*th; but only the *k*th piece is available for the *i*th provider, therefore, the marginal utility of the *k*th piece of information is insufficient by itself because the *j*th buyer can not engage all data providers and get all data, so the *k*th piece of information goes unpurchased.

### **3. Voluntary exchange on the supplier side is limited by the competitive lack of “trust.”**

If two providers are in competition (but not on price) in one area for market share, personnel, public recognition, government favor and they view each other as predators....they are unlikely to engage in optimal mutually beneficial data exchange. Each knows what value the information they are getting is to them. Each knows the cost of providing the information. In a non-predatory market that would determine the price and drive the exchange. However, each seller does not know to what degree that information in the other's hands will be a detriment to them. It could be used to scare off their customers, discredit them to their investors, steer employees away, and cause the lawyers to sue or governments to descend on them. Therefore, a very large risk premium is attached to the price and much data whose negative use is undetermined will never be put out. The result is again a partial and fragmented picture.

However, if government were to collect all from all and supply to all, there are no hidden risks; just real ones in terms of complete disclosure and public scrutiny. Yet this is not going to happen in a banana republic.

#### **D. What Needs To Be Done?**

Wisconsin at one time was on the road to “progressive health data”, where government struggled with private sector control and restriction and sometimes won partial victories; but at least it was a national leader in moving towards some of the central principles of health care democracy. What are the progressive principles of a health care data democracy defined in the first pages of this essay that need to be restored, so Wisconsin can move back to leadership and away from being a “laughing stock of the health data community”?

- The government as the representative of the public has the right of access to all health data in a state,
- The public resources (tax revenue) exists to collect, store, analyze and disseminate that data
- The government carries out those functions or manages competitive bid defined subcontractors.
- The government has unrestricted use of that data for public policy setting, regulations, utilization review, quality enforcement, rate setting, health planning authorization of facilities and capacities and workforce training and placement.
- The free and on-demand access of citizens, academic institutions, businesses and community organizations to that data without restriction as to use as long as consumer health data is not identifiable.
- The public data adhere to the principle of the removal of consumer identity or confidential information linked to individual consumers, but providers are not a protected class as they are in a public business: health care.

That is it. Without these progressive principles (which exists in most civilized nations with universal health care) a society is a health care data Banana Republic. Anyone from outside the United States and from a “progressive health care nation” looking at this nation and its approach to health data would also conclude that the dominance of health care providers over health care data and the lack of public health infrastructure to develop and use population health data are clear indications that we live in a health care data Banana Republic.

In the future if Wisconsin ever returns to the route of progressive health data democracy then it would rebuild its public sector infrastructure so that:

- Those who own health care would not be in political control of it or its data and the use of that data.
- Health data policy would be set through public discourse, not private lobbying and those providers who disagreed with the public analysis of the health care data could always engage in public discourse as counterpoint.
- Legislative actions and judicial rulings would be expansive, rather than restrictive in the area of health data and those providers who objective to the use of that data can always bring their issues to a court for public resolution.

## **II. What Does This Imply About the Direction of the State of Democracy in Wisconsin?**

What is a more interesting question is whether Wisconsin’s decline in terms of its health data direction towards El Salvador and away from Progressivism, is in fact a predictor of the greater future of Wisconsin as a health care democracy and more seriously the political health of Wisconsin as a democracy.

A democracy can take a thousand forms over history and across the globe with some progressive and some not so progressive. Its typifications are not elections, parliaments or being able to stand up (not in mass media) with alternative views (as long as they are ineffective in challenging power). Most nations have elections and some times the winners even reflect popular will. Almost all nations have parliaments. Sometimes they even represent their constituents. Various levels of political free speech and the right to politically organize exist.<sup>3</sup> In some other societies the concept of democracy even makes it into social life, the corporate boardroom and the shop floor on an everyday basis, rather than being restricted to once every two or four years.

Defining what a democracy is verges on the impossible; but it is possible to define what it is not. A Banana Republic is not a progressive democracy. There are a number of characteristics of such a political structure that have nothing to do with elections, parliaments and free speech. Most Banana Republics have all of these in one form or

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<sup>3</sup> Even in the United States they have existed in some form despite the Alien and Sedition Act, civil war time suspension of due process, the Palmer Acts of WWI, WWII Internment, HUAC, 250 years of civil rights violations, the Patriot Act and restrictions on state civil servants from talking to the press or going against party line.

another, but less in those that have some form of the word “democracy” in their national name.

#### **A. Banana Republics are based on:**

- Those who own the infrastructures and resources of society also politically control them.
- Social discourse is powerless to shape policy, which is merely the reflection of existing power relationships.
- The Judiciary is not independent of those who control the infrastructure and resources of society and its primary job is not the protection of human rights; but to protect private property, suppress underclass crime and make sure existing institutions are secure.
- The universities at the faculty level are what are called in the third world “A Comprador” or client class that is from, owned and solicitous to the elites, even if the students are revolutionary.
- There is some form of theocracy, even if it is secular, in terms of a caste of priests, funded pundits, oracles, credentialed experts, auguries, official opinion setters and sages who protect the people from dangerous knowledge and are deemed to be the only legitimately wise.
- All things are a commodity that can only be acquired monetarily, where prices are determined, not by true market forces; but set through political power and oligopoly leveraging.
- The press might be nominally independent, those not owned by the ruling Junta members, but out of fear and the need for advertisers they do not take strong adversarial or investigatory stances and tend to be bland and pro status quo.

In a Progressive and democratic society, as Wisconsin once was on the verge of being for nearly a century, there were forces that once opposed all of these characteristics of a Banana Republic:

#### **B. A Progressive Democratic Counterpoint to a Banana Republic requires:**

- The political process of a democracy in bring citizens into decision making is a counter weight to the influence of wealth and social power.
- A strong government in the form of an established, empowered and non political civil service. The first progressive reforms were to isolated government agencies from political appointments and reform them into civil service entities. The use of these government agencies as the implementation means of reform in a progressive democracy. They create what does not exist in a banana republic:
  - regulations that protect citizens and consumers,
  - taxes that redistribute income,
  - social programs to offset the consequences of class, race, geography, religious distinctions and discrimination and
  - mechanisms to create and distribute public goods free to all.

- Learned and open discourse in public forums actually shapes public policy as opposed to being just a politically correct shadow behind which the real decisions are made.
- The judiciary is not dominated in terms of either members or philosophy of those who own the infrastructure and resources of society as their role is to wade in against the rich and powerful and on behalf of the human and consumer rights of the masses of citizens.
- The universities at the faculty level become an unfettered voice for reform and community leaders of progressive and active opposition to those who own society.
- The priest caste (either religious or secular or political/academic/business demagogues) who are merely spokes persons for the elite are not allowed to monopolized popular truth. Through media regulation and investment in public information they are beaten back and knowledge is no longer controlled by special interests.
- Public purchase, public ownership and free public access to collective assets and services (such as health care) make the purchasing power of any individual irrelevant to their enjoyment of the public space and necessities of life, such as clean air and primary education.
- There is a crusading investigatory public press (“muckrakers” to the owners of slaughter houses) who go after those in power, those with privilege and those with wealth on any issues where the public good might be compromised rather than read AP releases and present the views of spinners on both sides without comment.

It does not take much current affairs knowledge to assess whether society is moving towards these or away from them, but an easier measure is to look to see if some of the main support structures of a Banana Republic are still in place. As an example of the difference between a progressive democracy and a Banana Republic, it might be instructive to look at the characteristics of one of the foundations of Wisconsin’s pre-1900 banana republic status and whether there are parallel structures in Wisconsin post 2000 after a century of progressive efforts.

### **C. How Do You Know You Are In A Banana Republic?**

#### **1. In 19<sup>th</sup> century those who owned the infrastructure of Wisconsin, controlled Wisconsin.**

Before Wisconsin even made the attempt to become “Progressive” in the late 19<sup>th</sup> century there was an industry in Wisconsin that worked to block that development. That industry had the following characteristics:

- It was a dominant economic influence in the state and a major employer.
- It sold its goods as a private commodity for the price that was all the market (what there was of it) could endure.

- The revenue generated by this industry was not only greater than all taxes collected, it was a shadow tax imposed on all, set by political power, hardly controlled by market forces and inescapable.
- Everyone in society needed the services of this industry and without it faced ruin.
- The industry was the leading sector contributing to major construction in the state.
- The industry was a leader in technological innovations
- The industry captured much of the educated human resources of the state.
- Those who owned the industry or senior managers were some of the best compensated individuals in society.
- There was a huge gap between what those of the bottom of that industry's workforce were paid and what those at the top were paid, despite the profitability of the industry.
- The industry was subject to oligopoly and lack of competition as there were very few in the business and the smaller entities were bought out by larger ones.
- The industry was a closely held network of corporations where its business dealings and knowledge of those were strictly private.
- The public was subject to price differentiation and discrimination that favored some (with market and political power) and exploited others (without market and political power). Also many prices, much less costs, were secret.
- The industry was "interstate" in nature which put in out of reach of any one set of state regulations.
- They were heavily subsidized at the state and national level with public resources.
- The industry had a great many accidents that caused the most injuries and fatalities of any one sector, but no public record or investigations existed.
- There were no public indicators or records of the quality or type and scale of services.
- The government at local, state and federal level was one of their biggest customers, yet lacked the leverage of many private customers.
- The industry was lightly regulated and controlled those regulatory entities. For example, they could build anywhere they wanted without governmental permission; but when they needed the power of the government such as condemnation rights, they got it.
- They had no public sector competition or counterpart.
- They could threaten the existence of towns by proposing to leave.
- The industry was largely immune to judicial revenue and indirectly controlled many judgeships in the state.

- They were significant contributors to elected officials and had recognized “politicians” as “their people.”
- They had powerful lobbyists and could get favorable laws passed.
- Their leadership praised “free enterprise, unrestrained capitalism, and the virtues of the private sector, while damning government, regulations and reformers as communists and anarchists.”

The list goes on and on; but in 1900 this industry was the “**railroad**”. It and the mining industry, timber and other industries made Wisconsin a Banana Republic of the “trusts”. They did everything they could do keep Wisconsin from being “progressive.”

The railroads were one of the leading industrial economic sectors. Before the ICC rate setting and trucks their revenues were generated by a near monopoly that allowed them to set their own prices. Their annual revenue was many times the public purse. Their private assets in terms of land and capital far exceeded public assets. No farmer or factory could get their goods to market without access to them. No store or citizen could access goods without them. Their bridges, track and facilities dominated construction as the largest single projects in the state.

Mechanical engineering advances led the industry as a technological growth center. The best of the schools of engineering, business and law were recruited. The structure of 19<sup>th</sup> century universities was also linked to the industrialization of railroads. Traditionally, lawyers read for the law without degrees and engineers came out of the army or the factory. However, at the end of the century the German university model of degreed lawyers and engineers was taking over. Being recruited by the railroad was a major goal of many of the new graduates. To the faculty of many land grant colleges railroads also represent “progress”, the closing of the frontier and a new concept “consulting” plus the hope they might be hired by Stanford, endowed by one of the Central Pacific’s founder. The difference between “progress” and “progressive” has never gone away. The huge houses of “railroad Barons” were either on a hill or a lake or both and they were a cities or towns leading citizen and controlled many other industries. They also loved going on the Grand Tour of Europe and making sure their sons went into the business.

There were few competing lines in a state and every year the big roads bought out the small roads, which is why the game of Monopoly has only one railroad on each side of the Board. They were for all purposes “public utilities”; but without public control. Commercial contracts were private agreements where no one knew the rates provided to others. Big industry got “railroad rebates”, while individual farmers paid top dollar, if they could even get on the manifest schedule dominated by large volume industry. The industry was a national web of interlocking directorates and subsidiaries immune from state regulation, if there had been any. The federal government gave them “free land” and states allowed them eminent domain while paying for much infrastructure, such as public road access to rail heads.

The “railroads” injured more passengers and killed more employees than any other sector with only mining ahead in per capita terms, yet little public data existed. In fact, there

were little if any public statistics on performance or even services provided. Railroads maintained that most citizens could scarcely read a timetable, much less understand technical engineering data. Many states had “railroad commissions”, which were industry dominated with little regulatory authority. No “government” railroads existed, yet they dominated the government in terms of influence in the legislature and Governors office to say nothing of local politics. Their corporate councils also tended to get the best judgeships and few ruling went against their lawyers that were the best money could buy. (Lincoln was a “railroad lawyer” for the Illinois Central and his son Robert headed up the Pullman Company.) Their lobbyists were never out of money for a good cause and they furiously opposed progressive political candidate. They were to a person conservatives, although a few of the third generation of rich heirs became liberals 75 years later. They were all for McKinley, although they would come to regret his vice president and his newly discovered “Progressive” views.

In Wisconsin, Robert M. La Follette ran as a Progressive” against the “trusts” and that included the railroads, the mines and the timber barons. After 1903 and for a decade in Wisconsin, and to an extent in the United States” there were increasing railroad government rate control, line approval, safety and charge reporting, and state and federal regulations.... The list goes on with the University of Wisconsin leading the way with the creation of national model legislation. The walls of the Economics Department in Madison are lined with the pictures of these leaders of reform and regulation. Not surprisingly the railroads and other big businesses waged unending political war against La Follette. They never gave up and just waited for the “progressive spirit to wane”, which it did in the midst of the patriotic gore of WWI to be finished off finally by Amtrak and Reagan.

This essay is not a history of progressive politics and big business; but the parallels to today’s health care industry are obvious. The difference is that health care industry is much larger, richer and more powerful than the railroads ever were. They also can not be reduced to ruin by the invention of the truck or the plane as each new health innovation is captured by the same industry. They as a whole have an everlasting monopoly on health care as long as it is a private commodity.

## **2. In the 21st century those who owned the infrastructure of Wisconsin health care, controlled Wisconsin health care and its data.**

“The Health Care Industry as the Railroad of 2000”

- They are the fastest growing and nearly the dominant single industry with close to 14% GNP.
- In Wisconsin \$25 billion annual is spent on health care where the size of general tax revenue for the state is only \$12 billion, despite the mythology of Wisconsin as a “high” tax state.
- Health care is also exempt from sales tax. As many provider organizations are formally “not for profit” and “charitable” institutions, although none are “for loss” organizations they are mostly exempt from income and property tax.

- Few have adopted the corporate model of the progressive era: a formal cooperative as that requires sharing net revenue with the consumers and governance.
- Without universal health care, which most industrialized and civilized nations have, all citizens still need access that is accommodated with cost shifting and an aging population insures increased demand; just as hordes of young immigrants meant the railroads would turn a profit in 1900.
- Cranes flying over hospitals and clinics, whose construction is unregulated, dominate many sky lines, despite over-bedding and physician excess supply in many areas.
- Health care is being concentrated in mega-systems and small market communities see a decline in resources, just as rural railroad trunk lines were abandoned.
- Physician income averages six-times the average family income in Wisconsin; but is nothing compared to specialties while many facility owners and operators nursing homes, hospital CEO's, HMO managers, clinic leadership and others are part of the 1% Bush's base."
- There is little price competition; but market share competition via building with debt and buy outs, as a handful of major organizations engulf small health care providers.
- Contracts, price agreements and business details are all proprietary information as only "public charges", which no one but the uninsured public pays, are known for only parts of the industry.
- Actual prices favor volume purchasers and discriminate against individuals.
- National organizations of both not-for-profit and for profit are arising and acquiring across state boundaries.
- Unintended consequences of failures of quality are extensive; but largely unknown and the body count is many times the railroads 19<sup>th</sup> century collective high water mark of 13,000 fatalities in a year.
- Regulation is declining and even government paid for health care has lost much of its regulatory teeth, while industry dominates the development of "rules" and "laws" dealing with health care at both the national and state level.
- Although government pays for 50% of health care the "public sector" delivering health care is limited and declining and of no consequence compared to the "private sector."
- Hospital, clinic or nursing home closure is civic death to many small communities and is used as a local leverage.
- Despite the "specter of malpractice" the percentage of total health care spending to litigation costs is not out of line with other industries engaged in endeavors that put human life at risk. Even surgeons pay risk premiums that are nothing compared to small plane manufactures.
- The "self regulated" bodies are notoriously weak in terms of sanctions.
- The health care industry is a major contributor to political office seekers, has some of the best lobbyists and can dominate individual members of legislature and other offices.

- The official provider associations and lobbyists are anti-government, anti-regulation, anti-disclosure, anti tax and have a philosophy right out of the 19<sup>th</sup> century, as if “progressive movement never happened in Wisconsin.
- Universities, rather than academic counter points to the medical establishment and the creators of radical reformers are now part of the establishment: generating employees for health care, accepting industry funding for research and most medical school physicians, scientists, nurses..... are an inherent part of that supply side industry.

The question is whether in 21<sup>st</sup> century Wisconsin the health care industry is the heir apparent to the 19<sup>th</sup> century railroad. That raises an even more interesting question as to whether the growing consolidation and inherent power in Wisconsin of the health care industry is not related to the slide of Wisconsin to more of a health care and health data Banana Republic than its progressive democratic past would predict. That topic is enough for many books; but some of that evidence partially resides in the issues discussed in Part I of this essay: the ever more contorted, restricted and declining role of government in the collection, control and dissemination of health data.

Whether health data democracy starts to return to Wisconsin is, therefore, a question of whether Wisconsin becomes a stronger or a weaker health care democracy and that depends on whether progressive democracy ever returns to Wisconsin as the force it once was. That is what these health data colloquiums and symposiums should be talking about.