

Health Care Informatics – Next Steps for “The Health State”

A Call for Discussion: A Hawaii Health Care Informatics Collaborative,
Opportunities for Health care, Research, Education and Business

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Presented: Tech Transfer Seminar, February 6, 2003

Hale Koa Hotel

Preface:

The concept of comprehensive health care data sharing is crucial for effective Medical Informatics – the study and application of computer technologies to health care. Such information sharing presents immediate and intuitive benefit as well as daunting obstacles that have long been recognized. Individuals and organizations such as physician groups, The Hawaii Medical Association, The Hawaii Health Information Corp., The Hawaii Outcomes Institute, The Hawaii Medical Services Association, private insurers, business groups, City State and Federal Government institutions have been working over the years toward the functionality that is being suggested here. New and emerging technologies bring energy and motivation to the effort as these enabling developments bring the goal much closer to our grasp.

Emerging information technology developments such as broadband, reliable, affordable Internet access, the development and deployment of electronic medical record systems, the growth of Application Service Providers (ASP) and the explosion in biotechnology research and applications effect a change in the status quo.¹ We are compelled to look seriously at these new opportunities as they have far reaching potential effects on health care, education, research, and the economic development of our State.

The Healthcare industry is unstable, costs soar, medical errors occur at an unacceptable rate, providers and insurers debate over reimbursement, employers chafe at the cost of health insurance, the rural underserved seek access to specialty care, the economically disadvantaged seek any care at all. Health care information management promotes better health care management overall and can mitigate many of these effects.²

Information technology brings a whole spectrum of potential improvements to health care safety, accuracy, and efficiency.

Introduction:

Profound technology developments, a health care revolution, a need for new industry, a persistent economic downturn, and an apposition of events, offer significant opportunities for the health care system and the economy of Hawaii.

What follows is a call for discussion on the concept of forming a statewide health care informatics collaborative: A collaboration of people and institutions dedicated primarily to using information technology to improve the delivery of medical care, patient safety, convenience and

control, and secondarily dedicated to the development of opportunities in research, education and business.

The collaborative would act in a guided adjudicated, non competitive manner to share blinded clinical data, processing expertise, and clinical informatics expertise, as well as development, technology, and support costs, thus enabling us to translate developments into real world applications.

This preliminary document is a distillation of the thoughts and concepts of many, gathered over a number of years, in many different health care meetings and forums. It is submitted as a discussion piece, a starting place from which we build the concept, share information, find others with similar ideas, stimulate further discussion, raise the visibility of the concept, search for collaborators, and in general gather support and collect like minded individuals and institutions as we move forward in this effort.

The reader is encouraged to carefully consider the benefits and not think first of the barriers and obstacles. Though the barriers may seem overwhelming at present they will be overcome with perseverance wrought from the magnitude of the long-term visionary benefits.

The reader is further encouraged not to be “put off” by the scope of the document. Though the topic is presented in grand scope with a long-term vision, there are immediate and concrete benefits to be gathered along the way. The path must be designed to create small discrete projects that are “do-able” and that bring immediate utility. Further, plans must be scaled to allow assembly of these discrete projects to a more comprehensive and cohesive vision.

Those interested in pursuing this concept are invited to “join the movement.” Plans presented are preliminary and limited in scope. We are early in this effort that can only succeed with the best ideas and committed participation by the community at large.

Confluence of Factors and Events:

Technology Developments:

Telecommunications and Information Technology has developed with impressive rapidity allowing inexpensive and quality access to information. Connections that once commanded high prices are now quite affordable. High-speed connections to the home are even possible. Telecommunications and information technology enhances the sharing of medical data as it allows even the smallest of offices to benefit from electronic medical records (EMR's), expert systems, data-warehousing, digital imaging and telemedicine. Telecommunication and information technologies take clinical informatics beyond the walls of the single institution and enable higher order benefits to be extracted from shared clinical information.

The development of affordable, reliable, high bandwidth connectivity (big telecommunications pipes) enables a new emerging model: The Application Service Provider (ASP). The ASP allows one to partake of the service without having to have the complete infrastructure at every site. This allows sharing of expensive central resources in a distributed model, leveraging investment, generating affordability and creating business opportunity. This technology is taking hold in the non-medical environment and indeed is the model for how digital business will be handled in the information age.

Clinical Informatics is defined as the scientific discipline that studies the capture, transmission, storage, retrieval, processing, sharing and optimal use of clinical information, data,

and knowledge for problem solving and decision making. It touches on all basic and applied fields in biomedical science and is closely tied to modern information technologies, notably in the areas of computing and communication. This field is mature to the point that comprehensive electronic health records are possible; indeed, it will soon become the standard of care.² It will soon be required that clinical data shall be made available to improve the clinical safety, efficiency and efficacy of patient care, while improving the cost efficiency.¹ The Information age moved banking from pencil and paper to secure Automated Teller Machines and Verifone credit card checks, allowing safely shared confidential financial records across the globe. Medical information critical to our individual well being will be shared in the same manner.

Information processing through data warehousing and data mining allow significant benefits for individuals, patients, providers, institutions and communities to be extracted. Patient care today is very much based on information. Poor, missing, or unreliable data has been identified as a major cause of medical errors.² Avoidance of duplication, unnecessary studies and procedures, medical errors and complications with timely accurate information will show immediate economic benefits.²

Information Management in Healthcare: Database Management in health care has begun the process of developing systems and networks that enable secure and private compilation of data physically and “virtually” for sharing and analysis. Most recently data sharing using “Object Layer” technologies have brought new abilities and has been used successfully in some states to share data over disparate systems for discrete uses such as bioterrorism surveillance and immunization registries.

Significant data sharing in the community already exists. Hospital data as well as insurance data have been shared with great benefit in the past. The Hawaii Health Information Network and the Hawaii Outcomes Institute have invested in this area. The Hawaii Medical Service Association has long been using claims-made data for analysis. The knowledge, expertise, and experience of all these areas need to be partnered with others in a collaborative effort.²

Bioinformatics is defined as the use of computers in solving information problems in the life sciences. Mainly, it involves the creation of extensive electronic databases on genomes, protein sequences, etc. Secondly, it involves techniques such as the three-dimensional modeling of biomolecules and biologic systems. Bioinformatics holds the promise to generate a biotechnology revolution, rivaling the digital revolution and even the industrial revolution. The faster than expected progress of the Human Genome Project brings new knowledge and capabilities. The potential of these developments could drive biomedical science to the “next level” of human benefit.² Hawaii desperately needs to be a significant national player in this arena and efforts are underway at the University of Hawaii to develop in this area

The Electronic Medical Record (EMR): The written medical record has evolved in recent years from a system that once documented visits as one-line entries on a file card to a required extensive written record. The next clear step is a digital electronic record that enables information processing that moves medical care into the “information age”. Computerization brings higher level functioning starting with basic improvements in rudimentary functions such as legibility, communication and sharing, reproducibility, and searching, to more sophisticated

data warehousing and data mining, and even to higher level potential such as the application of machine learning and artificial intelligence.¹

To date, the electronic medical record has seen limited deployment outside the government sector.³ This technology has been available for some time, but only now are there signs of a growing trend for adoption. There are many barriers to adoption of the EMR one of the most significant has been the cost.¹ The record evolves and slowly grows in use and sophistication but is being recognized as a requirement for the near future.¹

Hospital Clinical Provider Order Entry Systems are becoming common in our community. Expansion of these systems to include EMR for inpatient as well as outpatient systems will provide digitized medical information allowing institutions and individual practices to participate in data sharing collaborative ventures.¹

CPRS-VistA an Open Source Health Care Information System: Due to expense and other barriers EMR's have enjoyed their greatest growth in the government sector. The largest, most comprehensive and sophisticated system has been developed at the Veterans Administration (VA). The VA has developed the Veterans information system technology Architecture (VistA) that has been successfully deployed for a number of years at the largest centrally directed health care system in the United States.³ It has 250,000 users with millions of covered lives at 172 Hospital Medical Centers and 400 ambulatory clinics, nursing homes, and other institutions. It is deployed at non-VA hospitals and clinics and in other countries. Most recently, our own DoD/VA Pacific Telehealth and Technology Hui (Hui) is nearing completion of an installation of the VistA system at the LBJ Tropical Medical Center in American Samoa.

VistA has a distinguished performance record and is a proven product with a robust development capability. VistA is a program that was developed at government expense is available to all under the Freedom of Information Act (FOIA). Though FOIA available, VistA at the VA runs on proprietary operating systems that recently have become more expensive.

Another enabling technology is one we have constructed here at home. The DoD/VA Pacific Telemedicine and Technology Hui, working with other companies and organizations, has successfully ported VistA into an open source software environment that makes this program available "free" without paying for licensing and royalties. This in addition to the proven ability to deploy VistA over distance, and the development of application service provider business models, goes far to overcome the cost barriers to EMR adoption.

The Hui has been working to encourage the development of a local business model that can provide a company or companies able to support VistA in its open source environment.

Technology Convergence:

The convergence of these enabling technology developments lends unique opportunities for "The Health State". Bioinformatics, the "reading" of the genetic code, brings the possibility that we can know "how" our genes control our physical existence and "why" our bodies perform the way they do. We can "read" and observe the molecules and markers, but for the science to progress these changes must be correlated with human physical attributes. These attributes, for example, our height, weight, allergies, family histories, susceptibility to disease, propensity to cancer, responsiveness to drugs and many others are described by the medical record. The computerization enhances this record more than just a simple conversion to a digital record. Growth in Clinical Informatics and Telecommunications enables the development of comprehensive electronic health records.¹ These records define our physical attributes in

exquisite detail and allow us to use that information to be processed in a manner previously not possible.

It is the convergence of Bioinformatics defining the genetics and Clinical Informatics defining our physical attributes that will allow medical science to jump to another level of capability and allow growth opportunities in bioscience. The intersection of Bioinformatics and Clinical Informatics is “where the action is” in bioscience for the foreseeable future. These developing technologies light the path of scientific, academic and economic growth. Hawaii must act purposefully to become involved in these fields.

Apposition of Factors and Events

Geography:

Hawaii has a unique geographic advantage that can raise our efforts above the efforts of others. Our ocean boundaries, geographic isolation, relatively small size, and ethnicity work to our advantage. Due to geography our population is relatively stable, it is difficult and expensive to even search for out-of-state opportunities, let alone relocate. Those who do leave often return adding more stability to the population. A stable population allows for more comprehensive information gathering as longer clinical records are richer in detail and define better the populations’ clinical attributes. Large urban centers with mobile and transient populations will find it much more difficult to maintain longitudinal records.

Ethnicity:

Hawaii’s unique multi-ethnic population offers advantages found in few other locales. A multi-ethnic stable population with superior data gathering capability enhances the value of the project and offers opportunities that will be difficult for other communities to match. Pharmaceutical and academic researchers could come to Hawaii where longitudinal information is documented to seek study subjects with select historical, physical, ethnic and even genetic attributes. A well-defined and documented volunteer pool of ethnic Chinese for example, in an accessible western environment with state of the art research facilities, would be a desirable test bed for a pharmaceutical company interested in developing a “customized” drug for a potential customer base of a billion in China.

Population:

Hawaii’s relatively small population, relatively few health care institutions, high degree of insurance penetrance and stable population make a state-wide collaborative “do-able” in our State if competitive forces and agenda’s can be controlled. Hawaii could become the first example of maximal use of data systems for health care at the statewide level.

Health Care in Hawaii:

In 1974 Hawaii boldly stepped forward with the nations first and only prepaid health care act requiring employers to provide health insurance for their employees. This propelled the development of our status as “The Health State” and many held up our health care system as a model for the nation. This exceptional vision, followed by action, resulted in the excellent level of health care currently provided in our State.

The 1974 Prepaid Health Care Act has fulfilled its promise and brought untold health advantages to our people. It continues to serve us well as the staff of our “Health State” banner. The health care landscape has changed dramatically since 1974. The severe unrelenting economic drought of the past decades has strained many facets of daily living in Hawaii, none greater than our health care system. Many of our health care institutions teeter on insolvency, and employers strain to maintain health benefits for their employees.

The health of Hawaii could be simply and significantly enhanced by the development of a statewide immunization registry. This is clearly an area where our “Health State” banner has become tattered. Immunization of the children in Hawaii is clearly of primary concern; and with falling immunization rates, bioterrorism threats, and new vaccine development all ages could benefit. A comprehensive immunization database would be a first and efficient target for the Hawaii Medical Informatics Collaborative.

Hawaii can once again step boldly forward, embrace new developments and concepts to lead the nation and refresh our “Health State” banner. New medical technologies outlined in more detail below promise to profoundly change how health care shall operate in the near future. Hawaii has the opportunity to take the lead in translating these developments to concrete applications in a comprehensive health care system.

Hawaii Economy:

As the world’s economy becomes a global one, Hawaii’s agriculture suffers at the hands of international competitors. The international leisure industry likewise offers many new alternatives to Hawaii. The diversified economy remains an elusive goal. Hawaii’s economy desperately needs alternative engines. Bold and innovative action coupled with vision and perseverance can make biotechnology such an engine.

Biotechnology has long offered the promise of clean, light industry with minimal infrastructure requirements similar to computing and telecommunications. With the maturation of technology opportunity awaits the development of expertise and experience in the field, an educated workforce, and entrepreneurs willing to take the risk of translating research into business applications and opportunities.

Revitalization of The University of Hawaii and the John A. Burns School of Medicine:

Biotechnology cannot develop as an industry in Hawaii without scientific expertise and a skilled, educated workforce. A robust university, committed to scientific excellence that has set the development of biotechnology capability as a development priority can foster this industry in Hawaii. There is great enthusiasm at our university generated by a new President and Chancellor and the dynamic leadership at the John A. Burns School of Medicine (JABSOM). The JABSOM emphasis on development of research capability and expertise will be a key factor for success. This discussion is founded in part on premise that JABSOM is successful in developing expertise in Bioinformatics as well as perpetuating and expanding that expertise beyond the university walls to the Hawaii business and economic community.

Industry could build this expertise as well if committed to staying in Hawaii despite significant advantages of moving to the mainland. We have seen successful ventures develop only to take their benefits to other communities. Investment in the University might be looked on as a renewable resource, ever developing more expertise and educated workers to feed the critical mass of the biotechnology industry in Hawaii.

Bioterrorism Readiness:

World events brought upon us new requirements to be prepared for the possibility of terrorist attack with large scale and small-scale health consequences. The possibility that infectious agents could be used in warfare and terrorism sharpens our need for sensitive, effective, comprehensive and coordinated disease surveillance systems.³ These systems have requirements that go far beyond our current public health capabilities and beyond the capabilities of public health systems that we recently desired. To address these requirements to the best of our ability requires not only technology, but also community and institutional cooperation. The data and telecommunications systems serve as the infrastructure for a readiness system that will only be as strong as our ability to work together as a community.

The need for preparedness motivates us to work together bringing opportunities for collaboration that will contribute to the success of the Hawaii Medical Informatics Collaborative.

Stake Holders & Benefits:

Patients and Health Care Providers:

The patient and the providers working together must be the center of health care attention, and as such the major stake holders.¹ A powerful force for change is the empowerment of the consumer. Patients deserve and will demand better service, better information, improved safety, first class efficiency and more control over their care as health care continues to become more a consumer “product”.² The industry must evolve to fill these demands and medical informatics will play a key role.

Lets us visualize the possible benefits of a fully developed, implemented, secure and modern health care information system:²

Safety:

- Safer and more efficient care related to record availability (no lost, missing, incomplete records).
- Legible records reducing error (drugs, procedures, allergies).
- More comprehensive in-patient and out patient records available with security and accessibility.
- Accurate records with error checking i.e. allergies, drug interaction, less risk as duplicative orders for medications, tests and procedures are avoided.
- Work process improvements allow reminders for follow up needs and to collect and track crucial information. Information processing to generate follow-up lists and reminders.

Quality:

- Adherence with clinical practice guidelines, automated systems that remind providers to help patients complete disease specific and patient specific care recommendations.
- Comprehensive patient customized disease monitoring with follow-up reminders and documentation.
- Access to selected medical information, controlled by the patient for travel and emergency purposes.
- Monitoring for “evidence based care” enabled.

- Population wide improved health care related to the ability to generate public health interventions for the community.
- After hours record availability for emergency consultation.
- “Panel or Practice” level monitoring of care delivery to identify missed opportunities to maximize care.
- Automated systems that monitor patients.

Efficiency:

- Convenient scheduling over the Internet and the World Wide Web.
- Up-to-date demographic, employment and insurance information entered by the insurance company that need not be re-entered by each provider, location, pharmacy and hospital when services are needed.
- Up-to-date and secure medical information such as lab results, x-rays and other information available to patient, and other patient authorized providers, monitored for appropriate content.
- Selectively shared information when referred to other providers, avoiding duplication of efforts, filling out repetitive forms, lost papers or mail.
- Improved hospital, provider and insurance company performance, as effectiveness can be monitored and corrective education applied.
- Cost avoidance as better information allows for choices and “shopping” for services and supplies.
- Improved provider efficiency through streamlined work processes, fewer “do-overs”, telephone “tag”, chart searches, document location, mailing, copying, insurance claim information searches and other office “busy work”.
- Better provider work tracking and reimbursement monitoring.
- Efficiency for Allied Health Care Professionals: Pharmacists, Durable Medical Goods Providers, Social Workers, Therapists (occupational, speech, physical).

Improved communications:

- Accurate and reviewed disease information for patient education in multimedia formats, screened and recommended by the provider.
- Secure medical communications – email.
- Web access to office information.
- Better information provided to patients on their disease condition, their results and reports so they can be more informed and active in making their medical decisions.
- Detailed written instructions and information on your condition medications procedures and follow, given to you when you leave the office to help you remember.
- Patient access to their medical information so they can monitor their compliance with clinical practice guidelines, with their level of disease control and their laboratory and consultation results.
- Opportunities for patients to become invested in their care – access to their records that document their status and progress provides more reasons for them to be active in the direction of their care.

Convenience:

- Patients no longer have to keep track of paper orders, reports, insurance cards and other documents that are often lost or forgotten reducing efficiency.
- Quick return of lab test results and other reports being misplaced then laboriously located.
- Pharmacy refills authorized automatically without phone calls.
- Quick resolution of provider and insurance payment disputes.

Other Stakeholders:**Hospitals, Community Clinics, Provider Groups and other Health Care Institutions:**

- Enhanced level of Community care with availability of accurate, timely, comprehensive and available information at point of care and for analysis.
- Specific, timely, tailored, comprehensive information, for clinical and administrative decision making, customized for your particular institution or situation.
- The ability to pool specific information with other clinics for umbrella organization use in clinical, administrative, fundraising and legislative activities.
- Improved admissions, discharge, transfer coordination with comprehensive health information available when admission decisions are made and at the crucial period just after discharge or transfer.
- Comprehensive in-patient and out patient data including Radiology and Laboratory studies available to enhance safety and reduce duplication.
- Admissions, discharge and transfer data available for billing and cross-referencing with business data for cost savings and cost avoidance.
- Hospital Information Systems and Provider order entry systems generate data for tracking business activity in services, consumables and productivity.
- Critical incident tracking and audit trail for error tracking and root cause analysis.
- Automated Laboratory and Radiology systems for improved accuracy and efficiency cost savings and cost avoidance.
- Data gathering for tracking services and workload for hospital personnel and consultants.
- Accurate community provider activity data.
- Improved accessibility with simplified interfaces allowing easy to use, secure, management access, to “drill down” analyze problems and seek solutions and improvements.
- Decreased liability risk with improved safety and enhanced audit trail.

Insurers:

- Real time activity data significantly improves overall information accuracy allowing use of real time activity enhancing “claims made” data.
- Improve accuracy of claims thorough comparison of those claims with real time data.
- Comprehensive information, beyond “claims made” data for better adjudication of claims, program, financial and actuarial planning.
- Community accepted “neutral” information from a “trusted broker” speeds discussions and negotiations by giving reliable information for use in discussions and negotiations.

- Decreased liability related to improved safety and error evaluation through audit trail and root cause analysis.
- Increased efficacy and efficiency of care reduces through cost savings and cost avoidance. Less duplication, fewer errors, improved outcomes all reduce cost.
- Accurate data to monitor patient requirements and cost and for negotiation with employers and providers.

Business:

- Increased cost efficiency of health care justifies and reduces health insurance premiums and allows better coverage.
- Improved service to employees by health care system increases productivity and return on investment.
- Better utilization information allows employers to offer more appropriate plans, services as well as identifies efficiencies.
- Comprehensive information tracking for workman's compensation services improving efficiency of care and reducing duplicative services.
- Improved employee health.

University of Hawaii:

- The development of a granular patient database with comprehensive information is an “enabling technology” with grand research applications. Comprehensive data from volunteers for specific projects and de-identified “pooled” data bring powerful opportunities for research in a variety of areas.
- A demographically and stable genetically diverse population with a phenotype exquisitely defined through an EMR, empowers Bioinformatics and defines opportunities for development of a biotechnology base. The intersection of Clinical Informatics and Bioinformatics defines our opportunity to develop in cutting edge, exploding fields of basic and clinical science. The development in these areas is enhanced if we can build a unique clinical repository enabled by our geography and ethnicity.
- Augmentation of University led initiatives such as Biomedical Research Infrastructure Network (BRIN) and Integrated Advanced Information Managements Systems (IAIMS).

Biomedical Industry:

- The development of research capability in Clinical Informatics and Bioinformatics in our community enables the maintenance of a “critical mass” of expertise in the community. A work force with training in these areas is maintained and opportunities for commercialization are brought to the community to enhance the economy. This coupled with recent enabling legislation provides fertile ground for a biotechnology industry to develop.
- Developing our capabilities in clinical and bio informatics and a comprehensive granular community wide database will create an attractive environment for leading biotechnology companies to come to work. Clinical trials would find this an attractive locale for the development of customized drugs. Here, a well defined, genetically and ethnically diverse local population represents similar populations in a global, international marketplace with emerging consumerism in regions with diverse ethnic and genetic backgrounds.

Information Technology Industry:

- Another area where “critical mass” development and limiting “brain drain” is crucial for business development is in information technology. Creation of new work opportunities and the opportunities for local companies to be involved in solving problems and answering needs in this new area will translate to opportunities to extend that reach throughout the islands and for export outside the state. Developing countries on every continent are recognizing the need for health information systems and provide opportunities for use of expertise developed in our environment.

High Performance Computing:

- As clinical and bio-informatics applications when developed to a high degree have significant data processing and storage requirements. Hawaii has been blessed with an outstanding resource in the form of the Maui High Performance Computing Center. This unique asset adds to our potential as a bio-informatics power that could significantly leverage our capabilities and answer the question “why Hawaii”. The development of mature bio-informatics capabilities, a unique multiethnic well defined clinical and genetic base and the computing power of one of the most powerful computers in the country combines to make Hawaii uniquely suited for development in this arena.

State of Hawaii Agencies:

- The State Department of Health as well as other health care institutions has plans for similar information gathering and processing development. Working coherently creates synergy, reduces duplication of effort leverages resources. Community and State efforts to accomplish similar goals should dovetail. A comprehensive clinical data system could contribute significantly to State of Hawaii efforts and indeed communication and cooperation at very least should occur. Ideally co-development and even adoption of the State as a “neutral platform” should be considered.
- Immunization tracking, disease prevalence monitoring, bio-surveillance, Department of Education health support are obvious areas where a state comprehensive data repository could contribute to state efforts.

Hawaii Medical Informatics Collaborative (HIMedIC)

Health Care Data Sharing Model:

Introduction:

Recent developments in technology that bring the capability to share health care data in a safe, reliable, timely, controlled, private and efficient manner allows us to seriously consider working together to share information. The benefits of developing shared data systems have long been apparent on a smaller institutional scale though significant barriers have prevented such development within health care systems.¹ It is felt that new technologies allow us to realistically consider this now achievable goal.¹ Health care systems, government entities and communities across the country are working toward similar systems.

Again, concepts outlined here are presented in primordial form to stimulate discussion, to interest like-minded individuals. The goal is to begin a flexible and inclusive process of planning that will culminate in a concept, constructed with care, that offers benefits for all with safety and comfort. This can only be attained through careful and deliberate planning, true to these themes, as we work together to the ultimate goal.

Privacy and Security:

Protocols, practices, regulations and guidelines in the age of HIPAA and an increased sense of concern over information practices are causing changes in how we handle information. We all look forward to a better definition of how these changes will affect our practices and daily lives. Certainly any community effort needs to respect the constraints and legalities required to maintain the highest level of security and privacy possible. To abrogate this trust we are asking of our patients and partners is to doom the project. Additionally, comfort in use of data by individuals and institutions needs to be respected and perhaps developed over time. The reader should keep in mind that these policies serve as a prime directive and will no doubt limit to some extent what can and should be undertaken. Over time as further experience is gained, procedures and protocols may be adjusted and perhaps enabling legislation will need to be sought, but a conservative approach to insure compliance and comfort needs to be a founding principle.

The formation of a strong and trustworthy Data Control Board, comprised of representatives of all participants, is essential to maintain comfort and proper practice and is a key element without which this project cannot proceed.

Patient control of individually identifiable data must be maintained.¹

Inclusion by Charter:

The very nature of the project requires a philosophy of inclusion. Data and diversity is the lifeblood of the project and inclusion of large and small contributors is a key to success. As a result a corporate philosophy of inclusion must be established and fostered. Disparate data systems and disparate views and opinions need to be adjudicated toward a cooperate effort. These are not small issues, indeed the success or failure of the project depends on the development of positive working relations and understanding.

Don't Start from Scratch:

The idea for an informatics collaborative is not a new one. The work of respected community institutions and individuals needs to be recognized and serve as the foundation on which to work with new opportunities brought by new technologies. We need to “stand on the

shoulders” of those who have been committed to this for some time and work to bring us all together to the common goal. Ground breaking work has been and continues to be done by: The Hawaii Outcomes Institute; The Hawaii Health Information Corporation; Hawaii Business Council; Hawaii Medical Association; Hawaii Medical Service Association; State of Hawaii Department of Health, Medical provider groups such as Hawaii Independent Physicians Association, medical individual medical clinics with data systems such as Kaiser and Honolulu Medical Group, business with data systems such as Praxis and Pacific Software as well as other individuals and agencies committed to improving health care and efficiency.

The purpose of this new effort is to support the efforts of these organizations and individuals, incorporate their work in a comprehensive manner to create the broadest possible view health care data, then share the aggregated and processed data back to the participants, with the added value of central data processing and technology, clinical informatics, business and health care economic expertise. Any of these organizations could participate to any acceptable degree as long as the tenets of security, privacy, protection of competitive secrets and comfort of all participants is respected.

Governance: Neutral Platform:

To foster broad participation and confidence the development of a "neutral platform" is required. Comparative information should not compare one group to another but rather serve as a yardstick to compare one group's performance to the entire population.³

Experience has shown that this collaborative effort cannot be "owned" or unduly influenced by individual entities with competitive agendas. As such, ownership or influence cannot devolve to providers, insurers, hospitals, business or other commercial entities. Such a neutral platform will need to be identified or developed by the HIMedIC collaboration. We might turn to the State Government, the University of Hawaii, or a well-constructed "nonprofit" serve as options to consider. Acceptance of the principle of the neutral platform is the first step. Federal agencies could be involved to the extent consistent with their missions.

Components:

The basis design for a health care data sharing enterprise is outlined in figure 1. At the core is a feedback unit with several components (concept modeled at The Pacific Telehealth and Technology Hui with the Tripler Army Medical Center and Veterans Administration Honolulu).

Figure 1. – The Core Element - Feedback Loop

Data Acquisition: Digital health care data is generated through multiple information systems; electronic medical records (EMR); hospital data systems; public and private laboratory, radiology, pharmacy systems; health insurance databases; city, state and federal health information systems.³ Security systems will need to be implemented with the guidance of the Data Control Board. Technology will be applied to “normalize” disparate data fields, to translate, or “map” to create coherent information structures. Automated object processing and CORBA technologies will be used to augment current mapping and translation techniques.

Though multiple information systems, EMR's and databases will be integrated, the task becomes more complex and expensive as greater numbers of disparate data sources are

incorporated. Greater value is gathered from larger databases than from multiple small ones. A balance will be reached between resource allocation and complexity of task defining a cost/value ratio that individual organizations as well as the Collaboration will use to allocate resources.

Data-warehouse: A comfort level in the sharing of data will need to be developed. Safeguards will need to be addressed with the recognition that a balance must be struck between comfortable sharing and functional limitations imposed by rules. Depending on level of comfort, shared data could physically reside in a central physical repository or remain distributed at local sites to constitute a “virtual” repository. The data could remain “blinded”, “coded” and protected with decoding capabilities residing only at the providing institution, practice or practice or “trusted agents” at a central location could adjudicate functions preserving a greater level of flexibility and utility.

Data Processing: A shared data processing unit with leveraged, hard to acquire expertise, blends the clinical information, processes it to extract knowledge from the data and provides expertise in clinical informatics, business practice and health care economics. This Smart Team of subject matter experts with experience with large population as well as small entity health care economics, provides “added value” with expertise that individual clinic entities may not be able to maintain and with further added value gleaned from their visibility of community wide blinded data.

This unit which likely should be centralized to maintain security and trust and would consist of experts at using data to create health care, economic and public health interventions that could be shared anonymously and non-competitively amongst the collaborators.

Two processing needs are identified. First is the actual processing of data for data construct coherence and extraction of knowledge from data. Expertise and experience in individuals able to combine, collate and link data in ways that bring out relationships that help define knowledge is difficult to find and develop. Designing interfaces to display such data and data relationships is equally important.

Additional “processing” with application of expertise in clinical informatics, business and health economics to the data processed above culminates in the definition and creation of “interventions”, recommendations for action to improve care made at the provider, small office, clinic, community, city, island or statewide level. Again, shared and leveraged expertise would allow for better-credentialed experts to participate.

Interventions: Recommendations are made at all levels of care to providers and agencies. These agencies may develop specific actions that change their behavior, policies, activities or practices. The impact of these “interventions” on the respective populations is reflected in changes in parameters and data continuously acquired.

Feedback Loop: The efficacy of interventions applied to health care in Hawaii is then monitored through the data collection system and aggregated for analysis in the data warehouse

completing the feedback loop. “Live” up to the minute data in the warehouse allows for additional value in the area of bio-surveillance for outbreak management and management of contagion.

Figure 2. - Database Amplification

Database Amplification, the Multiplier Effect:

The addition of data to the core database with the participation of additional collaborators and partners magnifies the power of the system. Additional data increases the discriminating “power” of the information. Wide participation of communities and institutions creates synergy as interventions are more efficiently implemented and monitored even outside of individual health care organizations and entities. With broad participation public health interventions can be more widely implement and their efficacy more easily monitored, generating the greatest community value.²

Wide participation with secure and noncompetitive sharing of data allows health care entities to safely compare their performance against a community yardstick to identify weakness and strengths in a safe and non-competitive manner.¹ As the database becomes more comprehensive, research opportunities develop with spin-off technology business that will support growth in the biotechnology industry that Hawaii.

Governance:

Management Unit: A management entity will need to be developed and tasked with the business aspects of maintaining the collaborative. This entity may be charged with management as well as development duties. A first task will be to design and maintain a business plan that will allow collaborative to be self-sustaining, charging user fees or developing other mechanisms as needed. This management entity will be charged with developing partnerships and opportunities for benefit of all partners as well as sustaining the collaborative.

Data Control Board: A controlling board with active member participation must be carefully constructed as the arbiter of fair practice and fair dealing. The Control Board should be made up of representatives of all institutions participating as well as at-large representatives of independent practitioners and patients.¹ Design and construction of the Board will be crucial in maintaining the comfort level of the participants and the patients.

The Data Control Board serves as the overall guiding body for the collaboration serving as a Board of Directors, with a charter of rules determining membership and participation, practices, influencing direction as well as adjudicating disputes.

Figure 3. - Sustainment

Certainly, benefits gained by the participants will generate cost savings and cost avoidance of significant benefit. Individual participants could be assessed user fees, processor fees, or consulting fees. Preferably other resources could be garnered that allow benefits to be

accrued without such user fees. Cost avoidance and return of investment at the state level could justify state spending in this area. Alternatively, opportunities for industry to benefit from the utility of the database could generate resources for the collaboration through user fees generated in clinical trials or other research endeavors. The public good extracted from shared information could command grants or federal funding for sustainment.

Of particular interest is the development of a Hawaii Biotechnology industry. A comprehensive, granular definition of each individual serves as an exquisite definition of the individual “phenotype.” As Bioinformatics grows and develops defining the “genotype” opportunities will abound at the intersection of clinical informatics and bioinformatics. It is here that the development of customized and “personalized” pharmacology agents and other treatments will develop as the next wave in medical care. A unique and comprehensive database will be a unique attraction for developers and position the State of Hawaii and the Hawaii medical community to participate in this coming revolution in health care development. Participation in these developments will generate economic activity, some of which could be used for sustainment of this data infrastructure and the Collaboration.

Next steps:

1. Identification of interested parties:
2. Convene Working Group
3. Formation of the Collaboration:
4. Resource Identification:
5. Definition of a Governance structure
6. Formation of a Development Team and Staff
 - a. Charter and bylaws
 - b. Business and Development Plan
 - c. Logistics and Technology Identification
 - d. Legal/Legislative Development
 - e. Communications
 - f. Infrastructure Definition
 - g. Personnel Development
 - h. Scientific Committee
7. Other

¹ Crossing the Quality Chasm: A New Health System for the 21st Century. Committee on Quality of Health Care in America, Institute of Medicine. National Academy Press. Washington D.C. 2001.

² Kohn, L.T., Corrigan, J.M., Donaldson, M.S., ed. To Err is Human: Building a Safer Health System. Committee on Quality of Health Care in America, Institute of Medicine. National Academy Press. Washington D.C. 2000.

³ Corrigan, J.M., Eden, J., Smith, B.M., ed. Leadership by Example: Coordinating Government Roles in Improving Health care Quality. Committee on Quality of Health Care in America, Institute of Medicine. National Academy Press. Washington D.C. 2002.

Figure 1. Central Data Repository Core Element
example: DoD/VA Project Feedback Loop

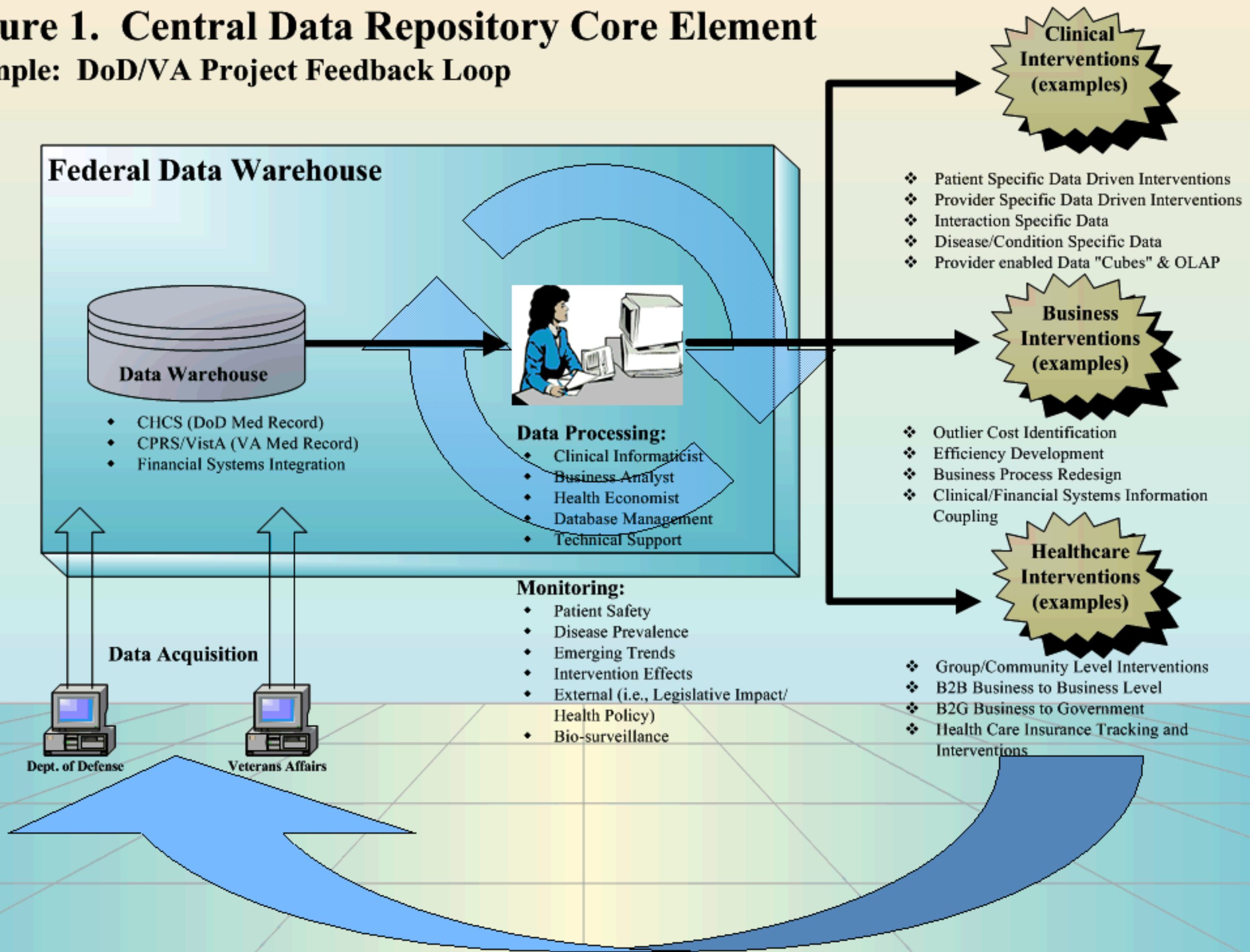


Figure 2. Database Amplification

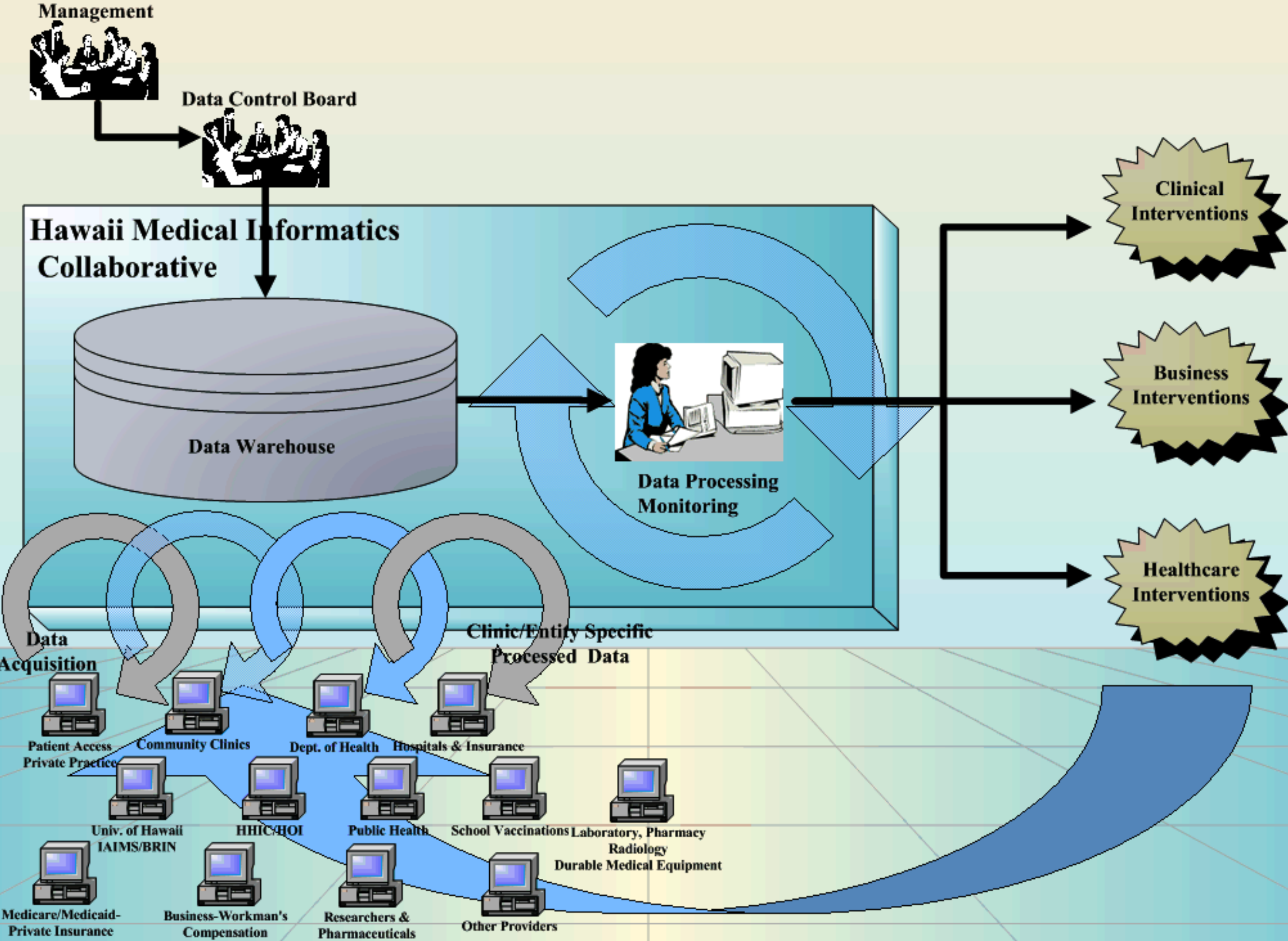


Figure 3. Sustainment

