“An Ethical HIT Capability”

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Ethics in health Information Technology, Problems and Solutions
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https://www.pinterest.com/source/lawyer-jokes.mytwotails.com

Where is the parking lot, again?

I hope to find my car ok when I leave.

My vain attempt to lighten the load!

Are our ethics on the menu?

You can't eat ethics!

All questions are good dumb question!
So keep them to yourself, OK?

Notable quote!

"Only tiny fractions of developers say that they would write unethical code or that they have no obligation to consider the ethical implications of code, but beyond that, respondents see a lot of ethical gray. Developers are not sure how they would report ethical problems, and have differing ideas about who ultimately is responsible for unethical code.“

https://insights.stackoverflow.com/survey/2018

Introduction

- The Institute of Electrical and Electronics Engineers (IEEE) recognizes that information technology affects the quality of human life throughout the world and commits to the highest ethical standards:
  - Ethical principles related to Health Information Technology (HIT) focus on increasing the value of care to the patient by assuring:
    - Every patient's privacy is maintained by securing their protected health information (PHI), and
    - That care safety, efficiency and effectiveness continually improve.
- In other words, the value of care to a patient rises as the security, quality, and affordability of that care increases, combined with ease of access to longitudinal information across the patient's plan-of-care.
- Unfortunately, such ethical lines have been blurred when HIT fails the citizen by enabling wide intrusions on individual privacy and not enabling ever-increasing care value to patients (V2P.

Health Care Today

- In our country, it seems that “Buyer Beware” tactics often rule the relationships among corporate America, government, the financial sector, health care, and even retail.
  - Identity theft, email theft, and voice-call capture are easily accomplished.
  - Devices designed to promote beneficial aid can now be turned into tools that violate privacy and individual rights.
  - Personal healthcare information is vulnerable and can be breached.
  - Management and use of clinical knowledge is inadequate when it fails to consider the whole person, does not take a longitudinal view, ignores care costs, and/or lacks personalized decision support that promotes V2P

Ethical Issues

- Ethical issues regarding HIT usability and usefulness, on the other hand, are rather recent.
- Ethical HIT refers to architectures and applications that:
  - Are easy to use,
  - Are interoperable and efficient,
  - Provide useful information in an understandable manner to all who need it, and
  - Support V2P decisions with evidence-based guidelines tailored to the needs of each patient.
- Today's HIT tends to be weak; it is unable to help resolve these deficiencies

Four Key Patient Principles Apply

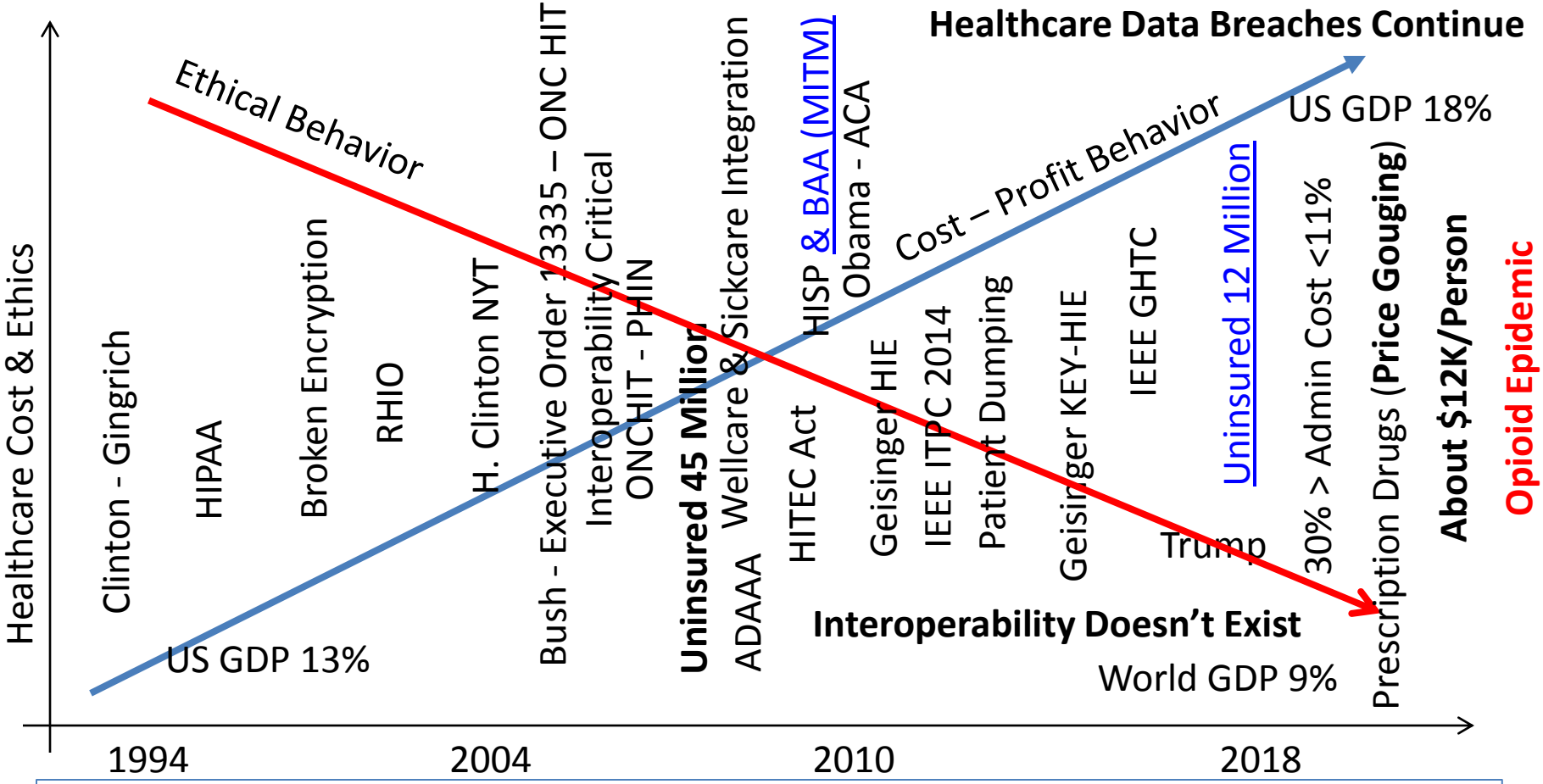
1. Justice:
   - HIT should give patients the authority to control the use and disclosure of their Protected Health Information (PHI).
2. Confidentiality and Trust:
   - When patient consent to share PHI is granted, HIT must protect patients' privacy with strong encryption, as well as ensuring the authentication and authorization of all persons with access to PHI.
3. Transparency for Personal Knowledge:
   - HIT should give patients easy access to their PHI and educates them about health status and care costs, risks, and options.
4. Anonymization:
   - When PHI is used for research purposes, HIT must first de-identify in ways that do not allow the PHI to be reconstituted from the base data.

AND……

Provider-Patient Principles Apply

- Non-maleficence:
  - HIT should have self correcting process that help prevent provider errors that may harm patients physically, emotionally, and financially (i.e., do no harm).
- Beneficence:
  - HIT decision support should help providers deliver high-value care to their patients.
- Risk-benefit analysis:
  - HIT should help weigh and balance possible benefits against possible risks and costs of an action.
- Double-effect:
  - HIT decision support should help clinicians avoid the error where two types of consequences may be produced by a single action.
- Professional relationships:
  - HIT should help provider teams to collaborate and coordinate care to help minimize errors of omission and commission and to continuously increase care value to the patient via continuous quality improvement (CQI) processes.
- Shared decision making:
  - HIT should enable patients and providers to collaborate in the creation and implementation of care plans.
- Autonomy:
  - HIT should support patients' right to make their own choices.
- Informed consumer:
  - HIT should help educate patients to become knowledgeable consumers of healthcare with strong voices in decisions about their care.

Unfortunately Ethics Lost



http://news.gallup.com/poll/225383/uninsured-rate-steady-fourth-quarter-2017.aspx

A Missed Opportunity?

- While conventional HIT has yet to achieve it, ethical HIT would help patients and their care teams in the following ways:
  - Perform competently (do the right thing, in the right way, at the right time)
  - Minimize errors of omission and commission (doing too little or too much)
  - Improve quality of life, or minimize loss of life quality
  - Help evaluate/judge care options
  - Weigh/balance the relative benefits and risks of a care plan (to be) rendered—including health problems and costs—as compared to other options (including doing nothing).
- Because these objectives have not been a serious enough focus of HIT to date, it is time to rethink our county's flawed direction and move toward development and deployment of ethical HIT.

We must address these areas now!

- Weak Security and Protection of Patient Privacy
- Control of PHI by Others
- Weak Usefulness and Usability
  - Lack of Adequate Clinical Decision Support & Shared Decision Making
- Processes of Standards-Making Bodies often Stifle Innovation and Increases Cost and Complexity

What do we need?

- Introduce an ethical Patient-Centric Value Chain focused on V2P
- Use HIT to transmit, transform, integrate and analyze data, and presented them as useful, actionable information that continually fosters V2P knowledge and decisions
- Promote HIT usability without disrupting efficient and effective clinical workflows

An Ethical HIT Capability[1] "Update"

- We construct this capability based on the promises of a new framework, Whole Person Integrated Care (WPIC)
  - **WPIC couples a Spreadsheet-based Software Framework (SSF) and value to patient (V2P) care delivery model to provide a collaborative platform focused on efficiency and effectiveness through evidence and consensus-based action.**
- We propose to fashion our Ethical HIT capability by building consumer centric applications on a secured node-to-node network

1 IEEE Schedule, Person Integrated Care (WPIC): A Healthcare Transformation Strategy Supported by a Novel Spreadsheet-Based Software Framework Published on August 19, 2017

The Goal of Ethical HIT

- Place the patient in the driver's seat regarding health and wellness education and management, early disease assessment and procedure awareness, plan of care development and treatment possibilities for specific conditions
  - **To accomplish this we must promote user understanding by maximizing knowledge transfers between patient and caregiver, as well as clinicians and researchers, using an intelligent person-machine-caregiver interactive interface.**

Can we manage chronic conditions (CC) using Ethical HIT? The CC impact on Health Care Cost. Why is this important? We present a hypothetical case for review.

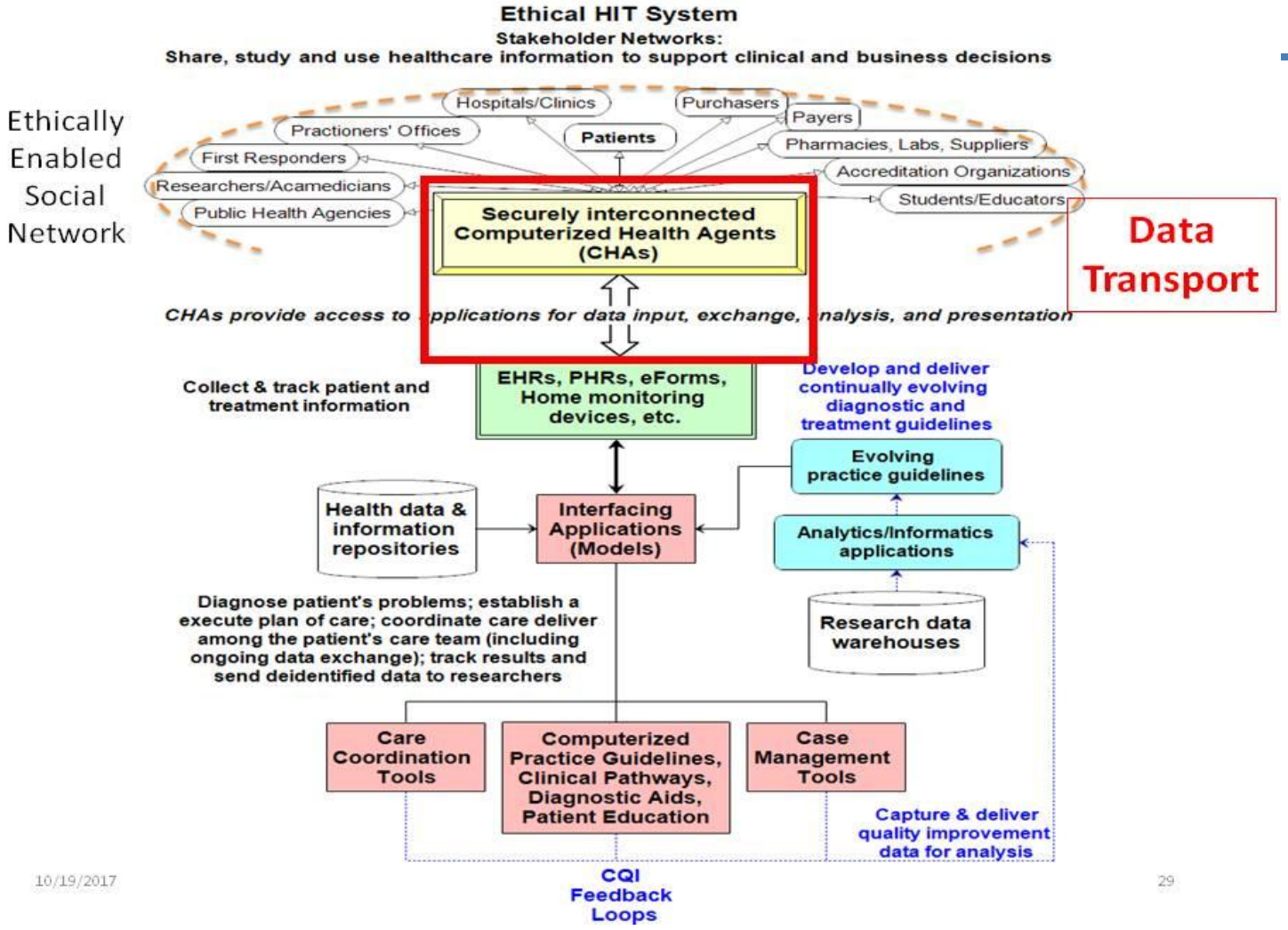
Building an Ethical HIT Capability!

- Piece Parts
- Extensible Architecture
- Patient Centric Applications
- The Internet of Things
- Network Design
- Proposed Enterprise Connectivity
- Financial Feasibility

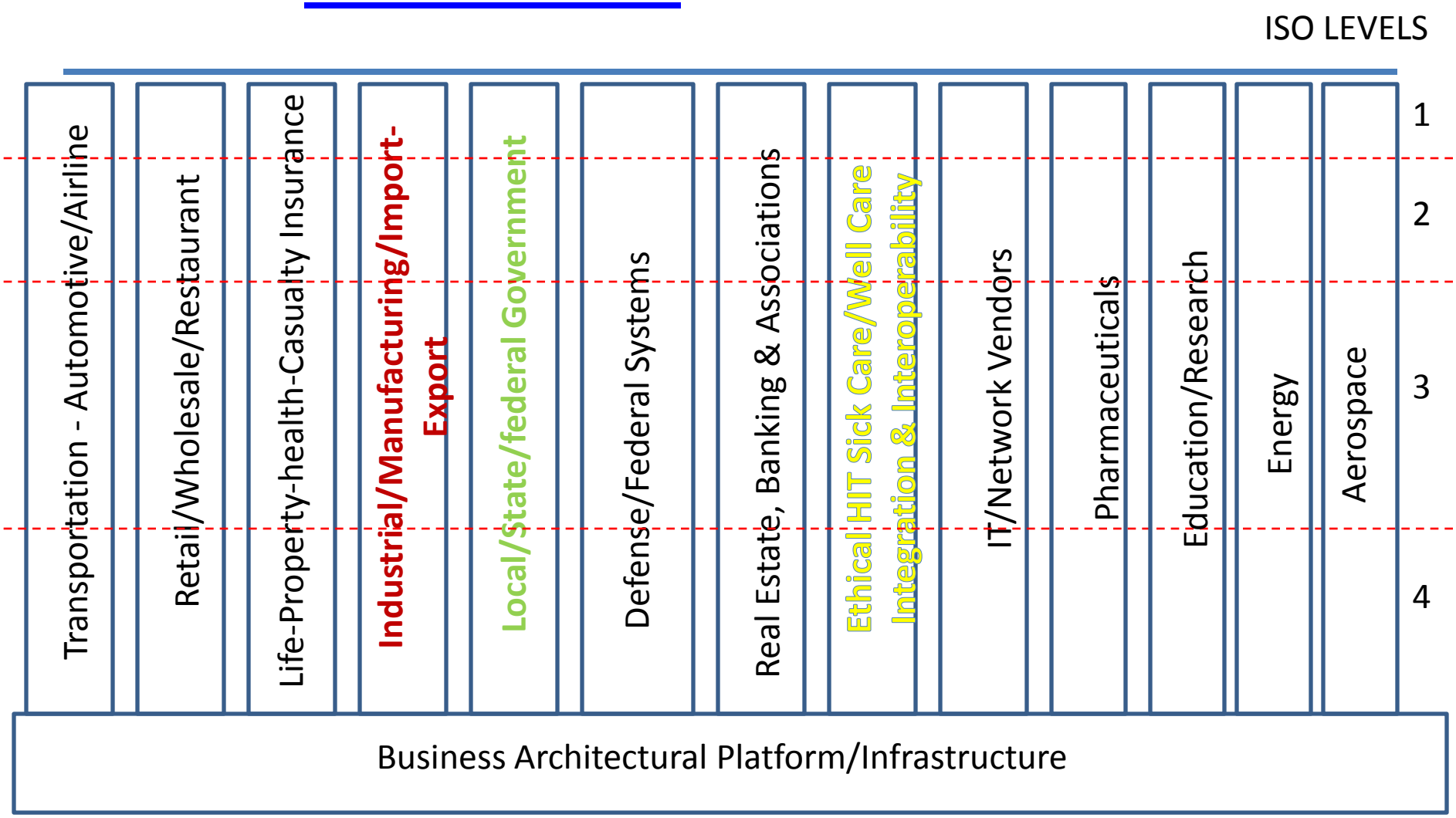
- A Hypothetical Case
- IEEE ITPC Conclusion (Time Permitting)
  - Ethical HIT Prototypes
  - EMOC Workflow Analytics (Example)
  - A Personal Experience
    - Advocate/Knowledge Worker – Providing Ethical HIT

What do we need?

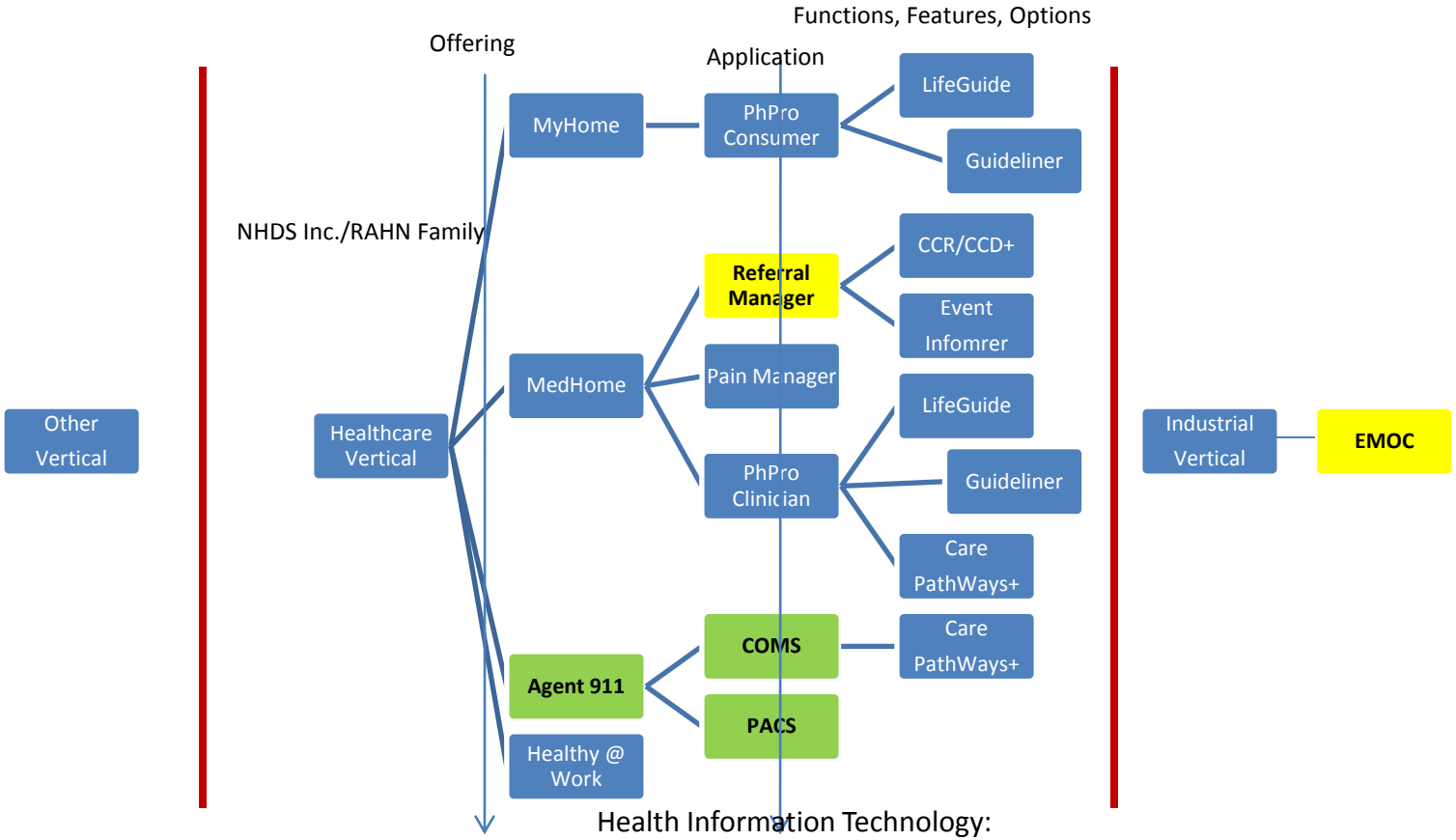
Piece parts!


Ethical HIT System
Stakeholder Networks:
Share, study and use healthcare information to support clinical and business decisions
Ethically Enabled Social Network
Hospitals/Clinics
Purchasers
Payers
Practioners' Offices
Patients
Pharmacies, Labs, Suppliers
First Responders
Accreditation Organizations
Researchers/Acamedicians
Students/Educators
Public Health Agencies
Securely interconnected Computerized Health Agents (CHAs)
Data Transport
CHAs provide access to applications for data input, exchange, analysis, and presentation
Collect & track patient and treatment information
EHRs, PHRs, eForms, Home monitoring devices, etc.
Develop and deliver continually evolving diagnostic and treatment guidelines
Evolving practice guidelines
Health data & information repositories
Interfacing Applications (Models)
Analytics/Informatics applications
Research data warehouses
Diagnose patient's problems; establish a execute plan of care; coordinate care deliver among the patient's care team (including ongoing data exchange); track results and send deidentified data to researchers
Care Coordination Tools
Computerized Practice Guidelines, Clinical Pathways, Diagnostic Aids, Patient Education
Case Management Tools
Capture & deliver quality improvement data for analysis
CQI Feedback Loops
10/19/2017
29

Extensible Architecture

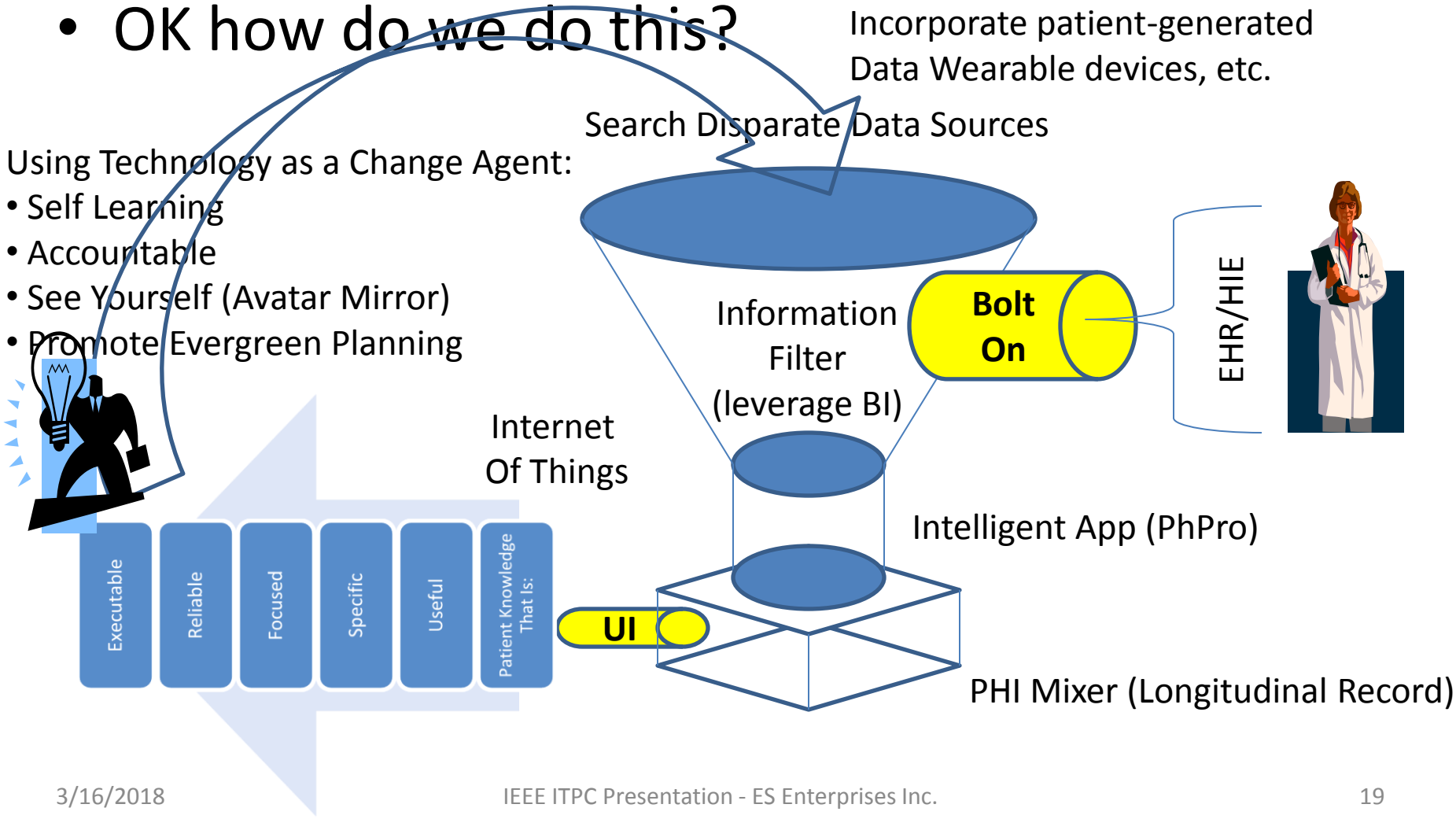


Patient Centric Applications

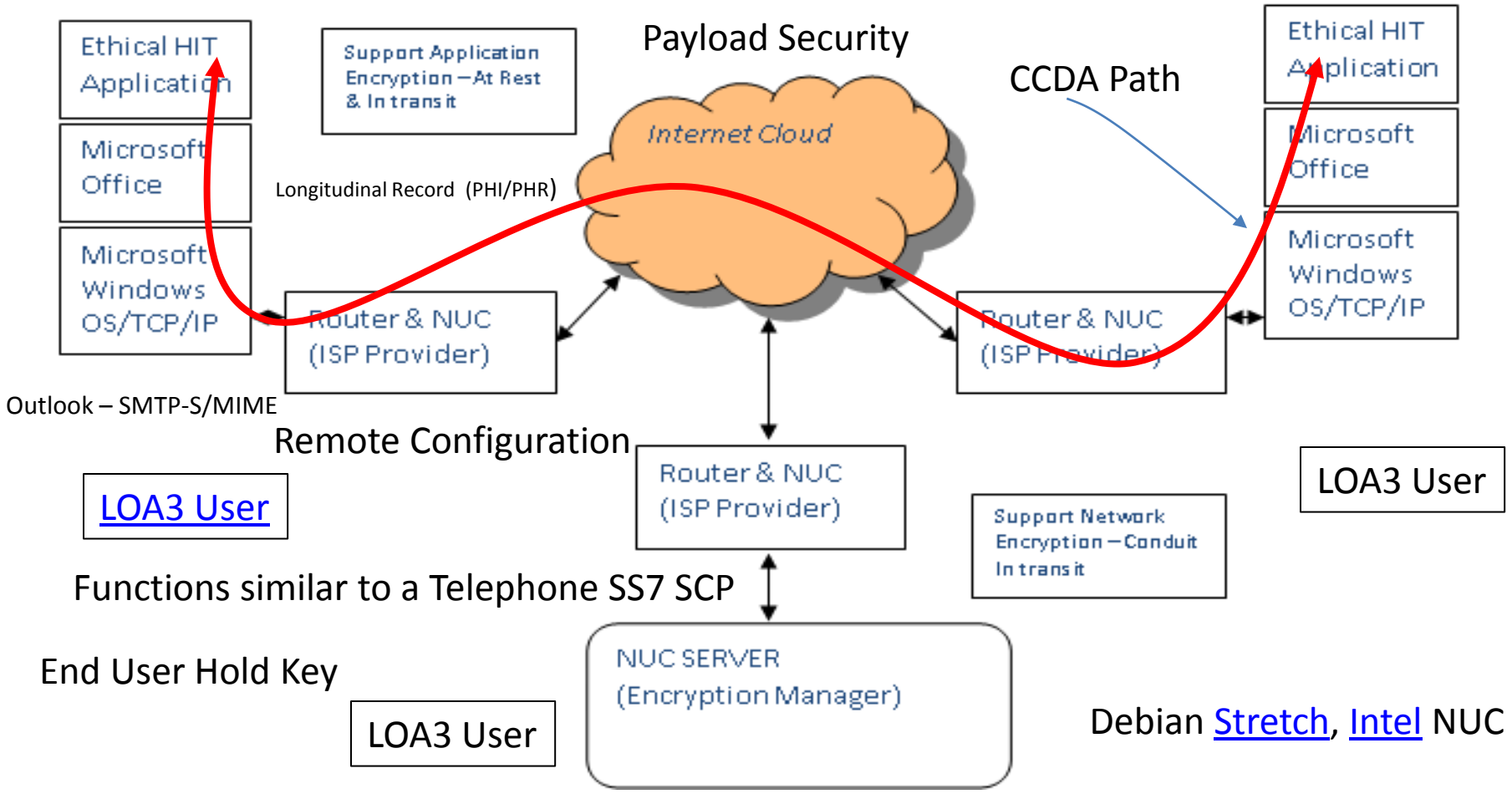


The Internet of Things

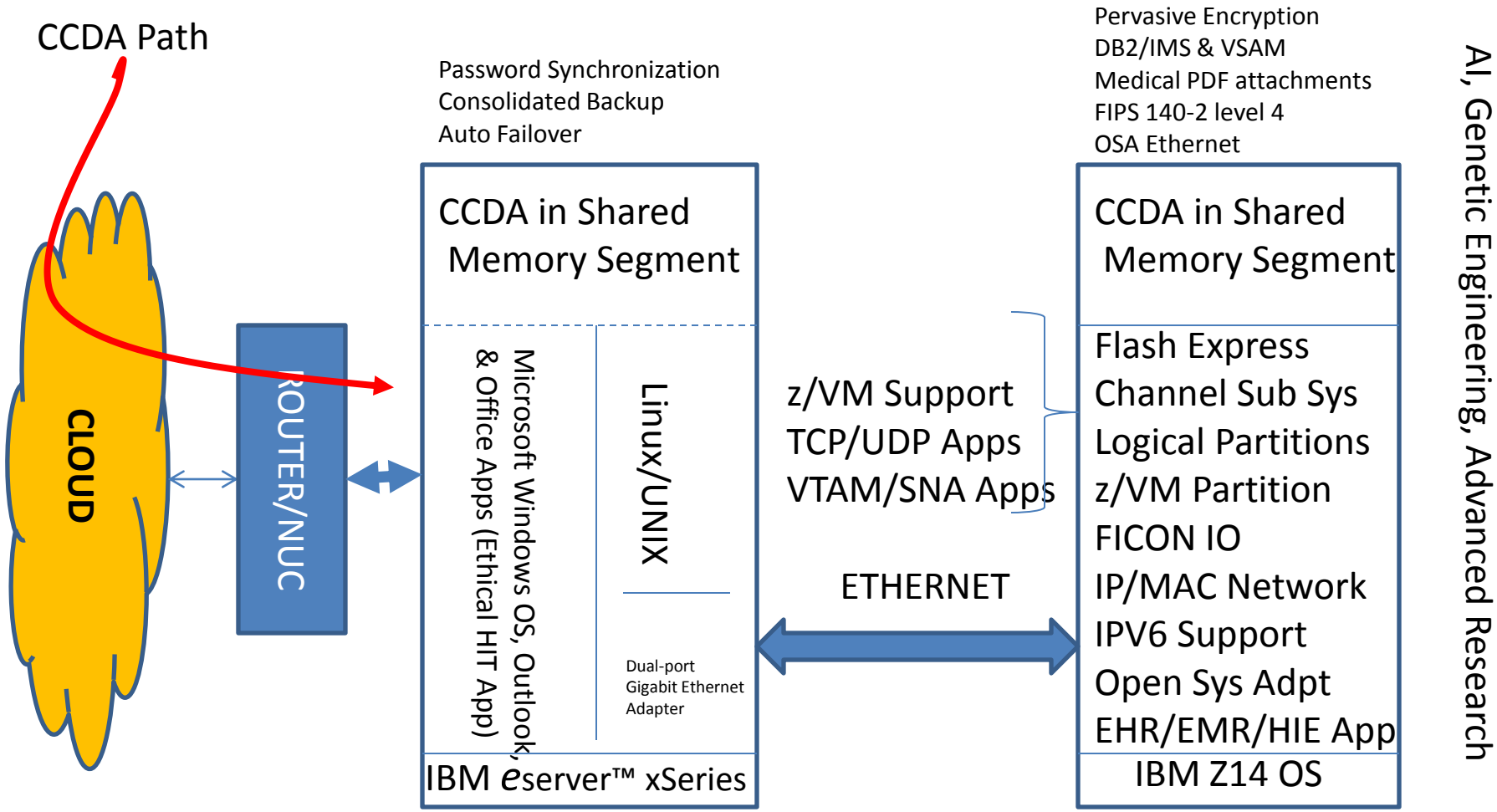
- OK how do we do this?



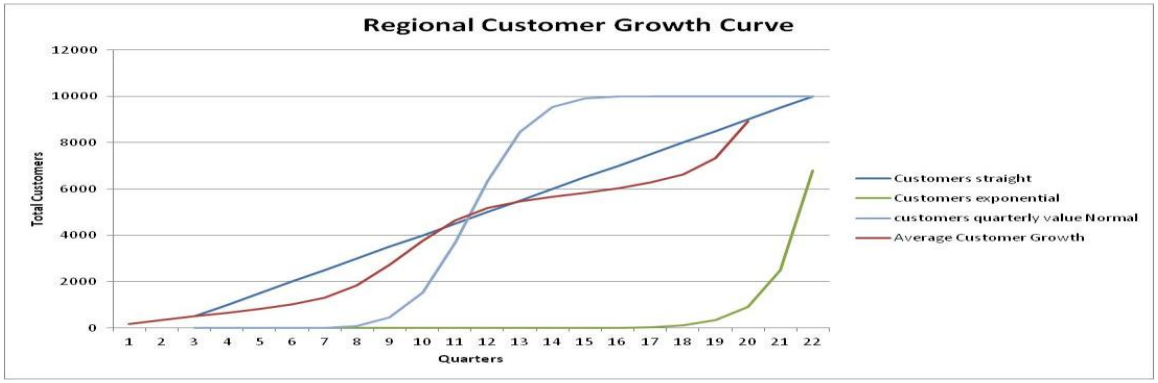
Network Design

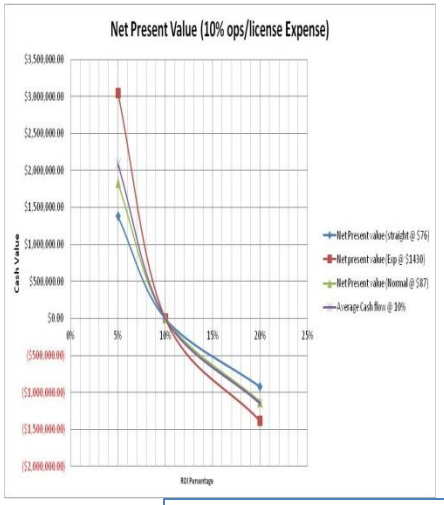


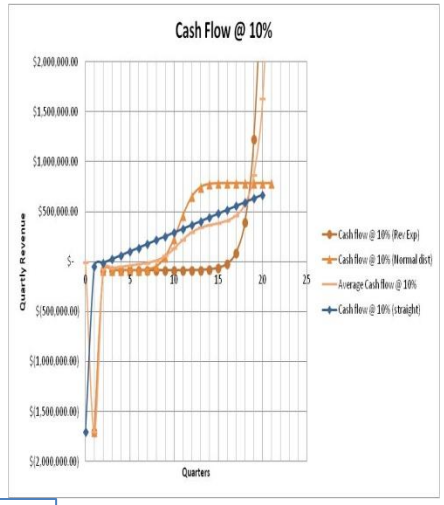
Proposed Enterprise Connectivity

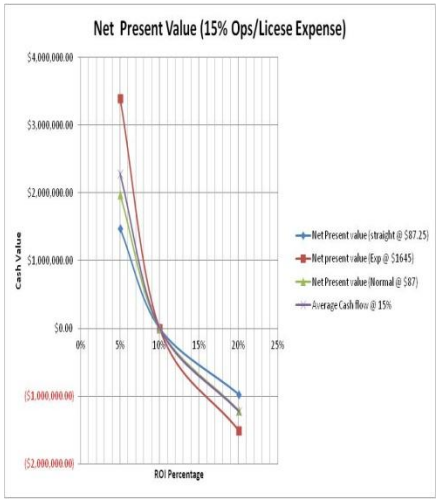


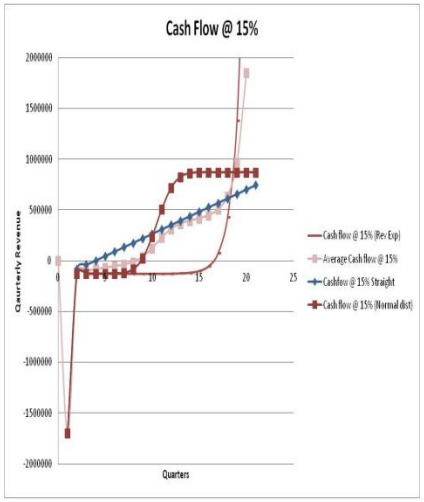
Financial Feasibility











Thank you M. Hoffman, IBM

IEEE ITPC Conclusion, Ethical HIT:

- Addresses the health care situation
  - High cost
  - Low value and quality of care
- Financially feasible
  - Subscriber model
- Technically feasible
  - Prototype Applications Tested
  - Enterprise Enabled
- Patient Centric
  - Ethically Sound Principles
- Drives the chronic, demand curve down
  - Empowering the patient
- Leverages Health Care Costing: Data, Methods, Current Applications
  - Joseph Lipscomb, PhD, K. Robin Yabroff, PhD, Martin L. Brown, PhD, William Lawrence, MD, MS, and Paul G. Barnett, PhD

"It can be hypothesized that QI strategies that have higher perceived value and that reduce workload (or at least do not add workload) are more likely to be adopted and ultimately sustained. To help organizations, managers, and quality improvers address this issue, we have developed a practical model—the Highly Adoptable Improvement (HAI) Model— and supporting tools to help embed the concept of adoptability into designing QI approaches and interventions." Highly Adoptable Improvement: A Practical Model and Toolkit to Address Adoptability and Sustainability of Quality Improvement Initiatives. Citation data: Joint Commission journal on quality and patient safety, ISSN: 1553-7250, Vol: 44, Issue: 3, Page: 155-163 , Publication Year: 2018 , Hayes, Christopher William; Goldmann, Don

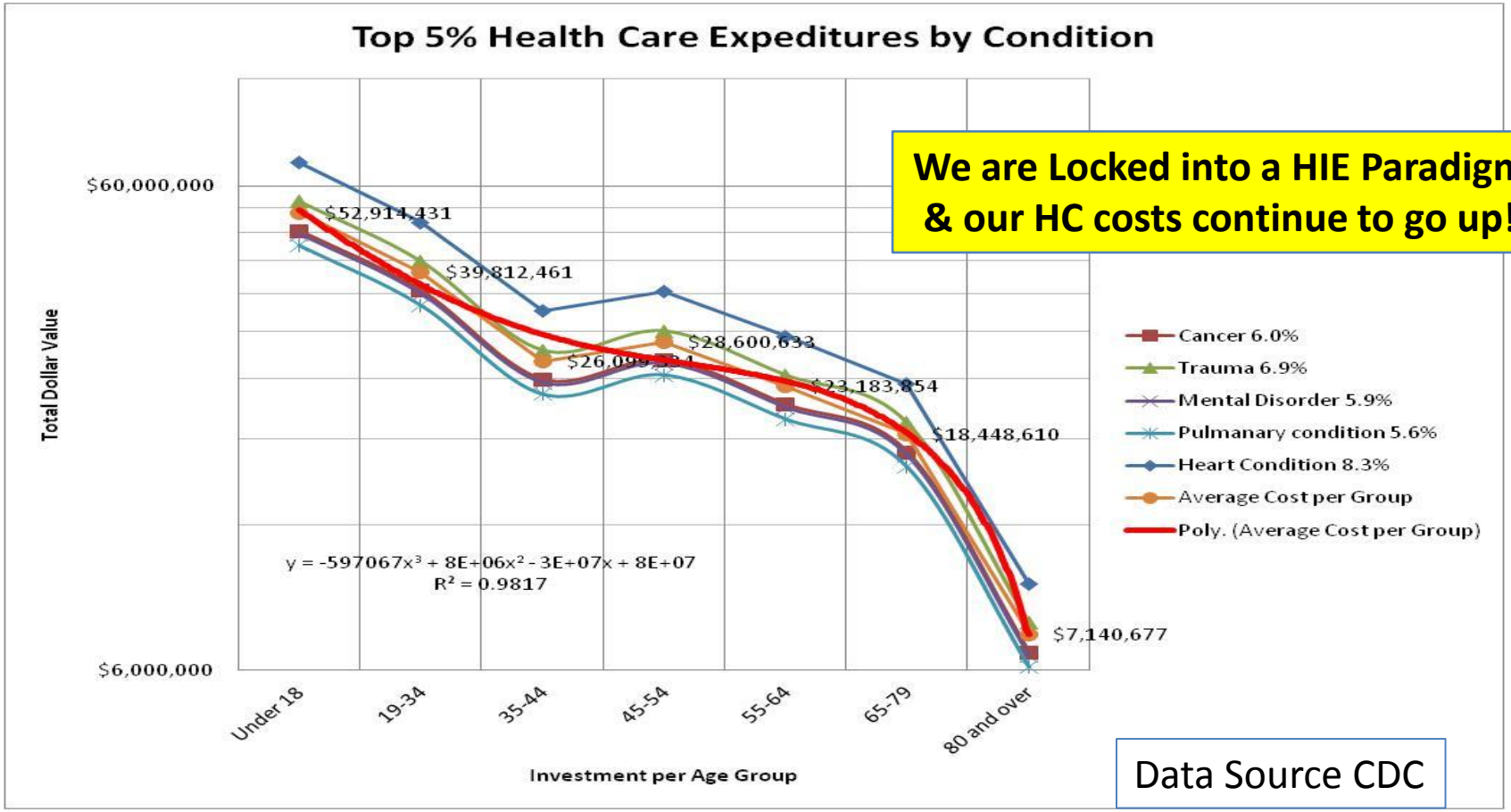
A Hypothetical Case

- Ethical HIT Capability Applied to Chronic Care:
  - Address Cost, Quality of Life (QOL) & Effectiveness
  - HC Cost & Top Five Chronic Conditions
  - HC Cost By Person & By Age Group
  - A Demand Suppression Model
  - Measuring Effectiveness & QOL
  - Some Potential Issues

Address Cost, QOL & Effectiveness

- Chronic diseases and conditions—such as heart disease, stroke, cancer, type 2 diabetes, obesity, and arthritis—are among the most common, costly, and preventable of all health problems.
- Ethical HIT Addresses these health problems because it:
  - Focuses on increasing value to the patient through improvements in QOL
  - Overcomes system design flaws that raise ethical concerns
  - Produces actionable information
  - Provides usability and clinical workflows accommodation
  - Empowers the patient (consumer) through education
  - Acts as a demand damper on unnecessary & excessive health care utilization
  - Enables collaboration between patients and their care teams
- Reference 1: Standardizing Patient Outcomes Measurement, Michael E. Porter, Ph.D., M.B.A., Stefan Larsson, M.D., Ph.D., and Thomas H. Lee, M.D.
- Reference 2: https://www.cdc.gov/chronicdisease/overview/index.htm

HC Cost & Top Five Chronic Conditions

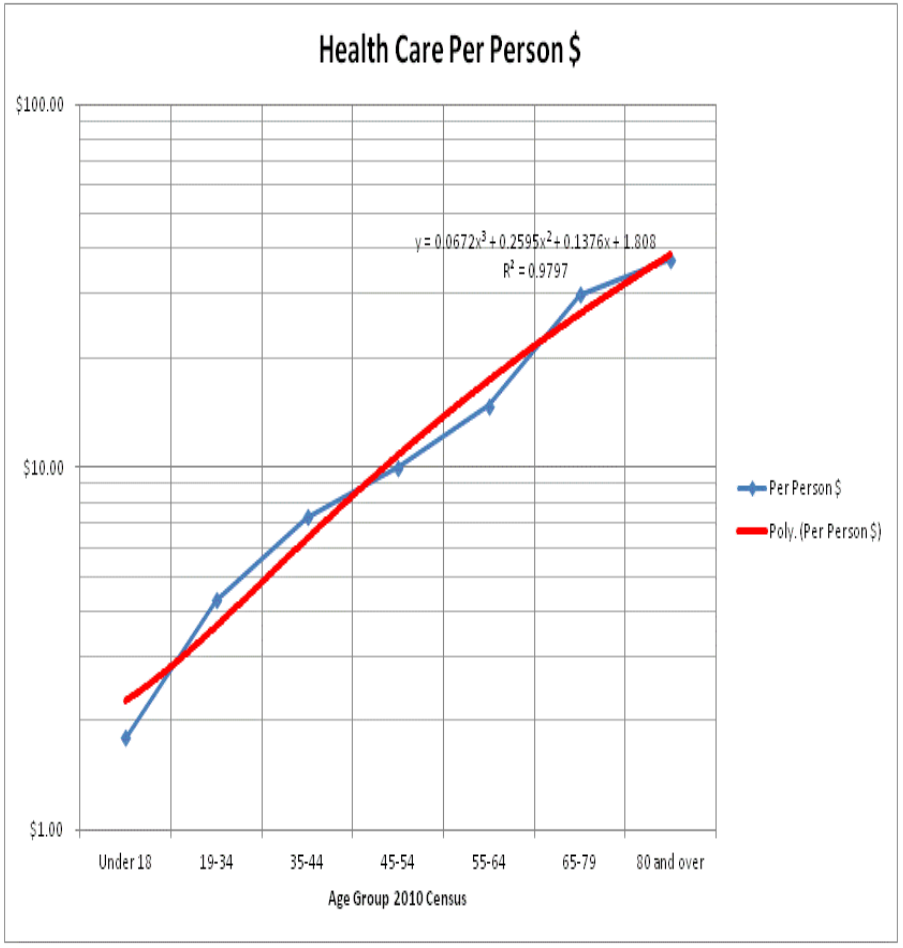


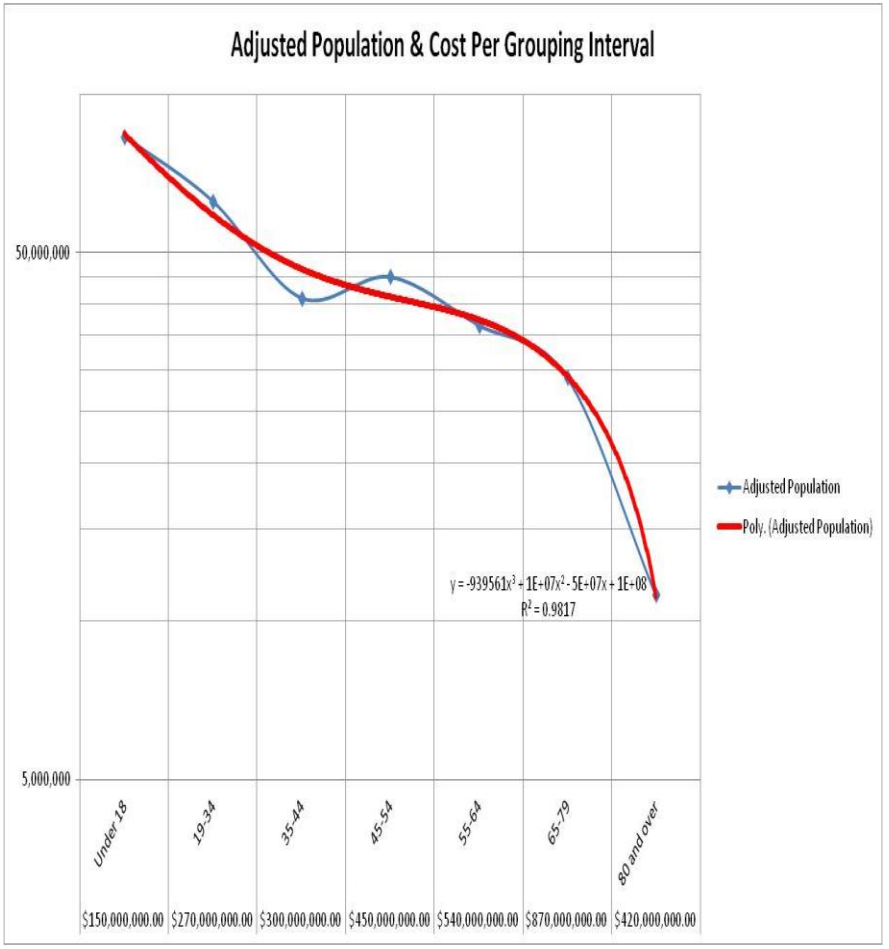
We are Locked into a HIE Paradigm & our HC costs continue to go up!

Data Source CDC

To Get Control of Cost: **Reduce Demand & Increase Value through Patient Empowerment**

HC Cost By Person & By Age Group



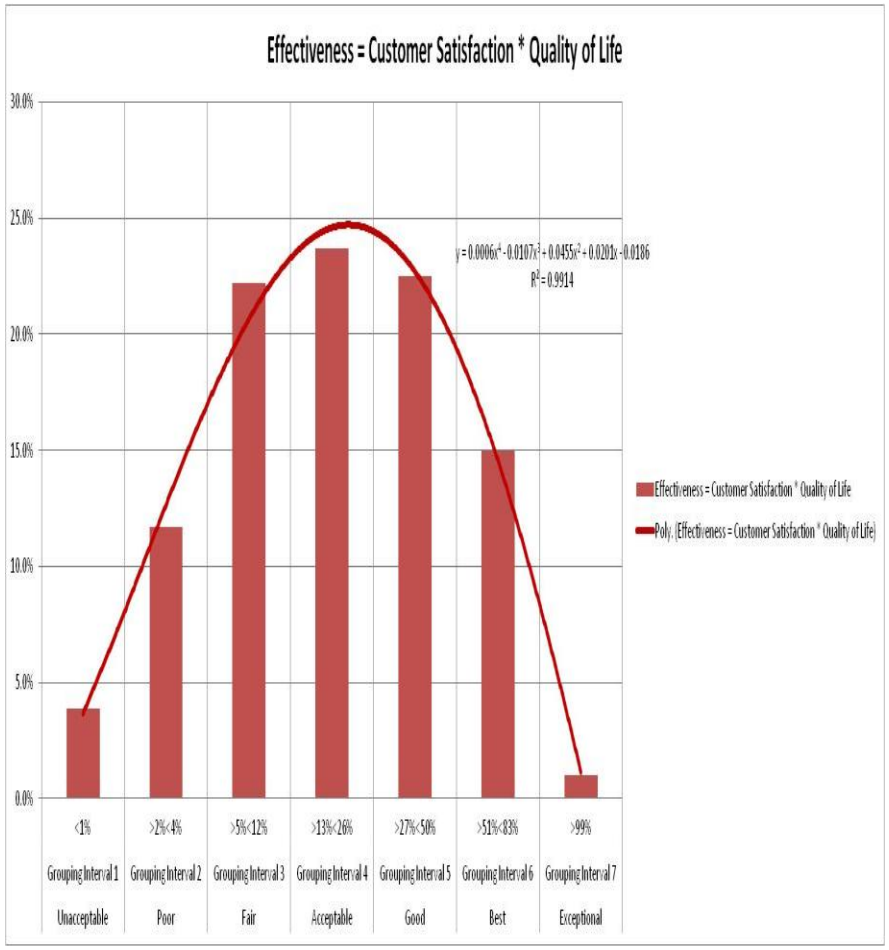


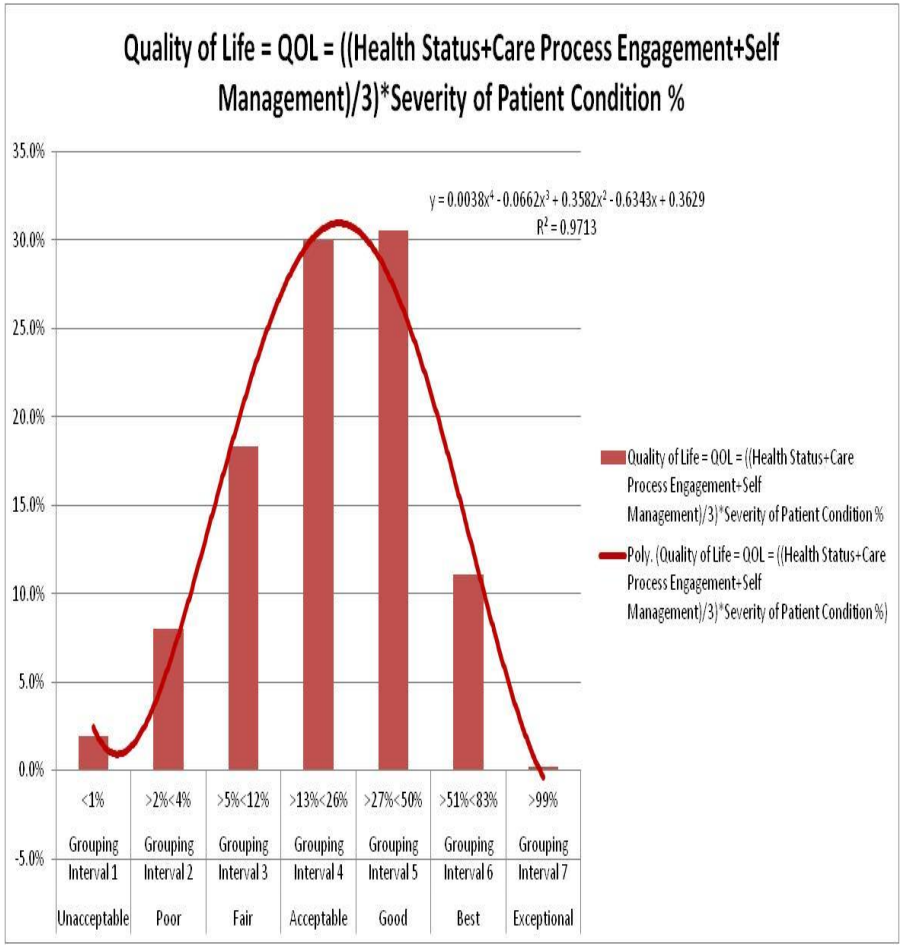
A Demand Suppression Model

- Quality of Life = QOL = ((Health Status + Care Process Engagement + Self Management)/3)*Severity of Patient Condition %
- Effectiveness = Customer Satisfaction * Quality of Life
- Perceived HC Cost = (Chronic Demand*Cost of Procedure-Practice Method)/Effectiveness
  - Chronic Demand = (Effectiveness * Perceived HC Cost)/Cost of Procedure-Practice Method
  - Chronic Demand = ((Customer Satisfaction * QOL)* Perceived HC Cost)/Cost of Procedure-Practice method
  - Chronic Demand= ((Customer Satisfaction * ((Health status + Care Process Engagement + Self Management)/3) * Severity of Patient Condition %) * Perceived HC Cost)/Cost of Procedure-Practice Method

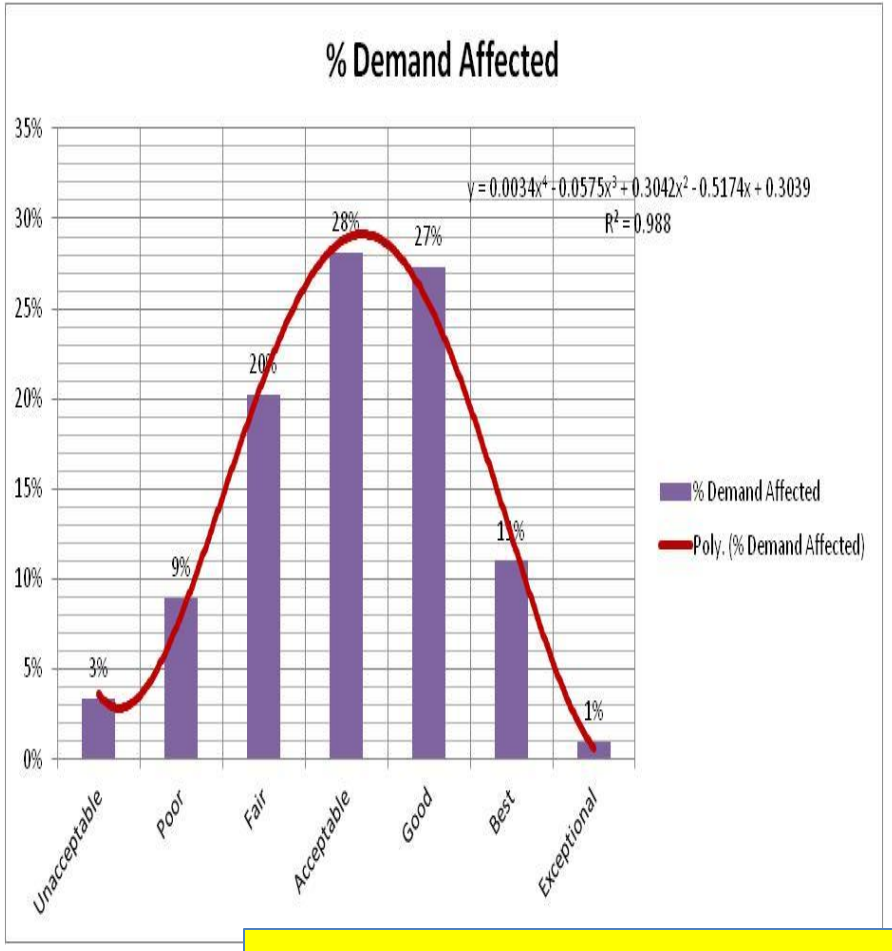
Note: Definition of metrics in flux

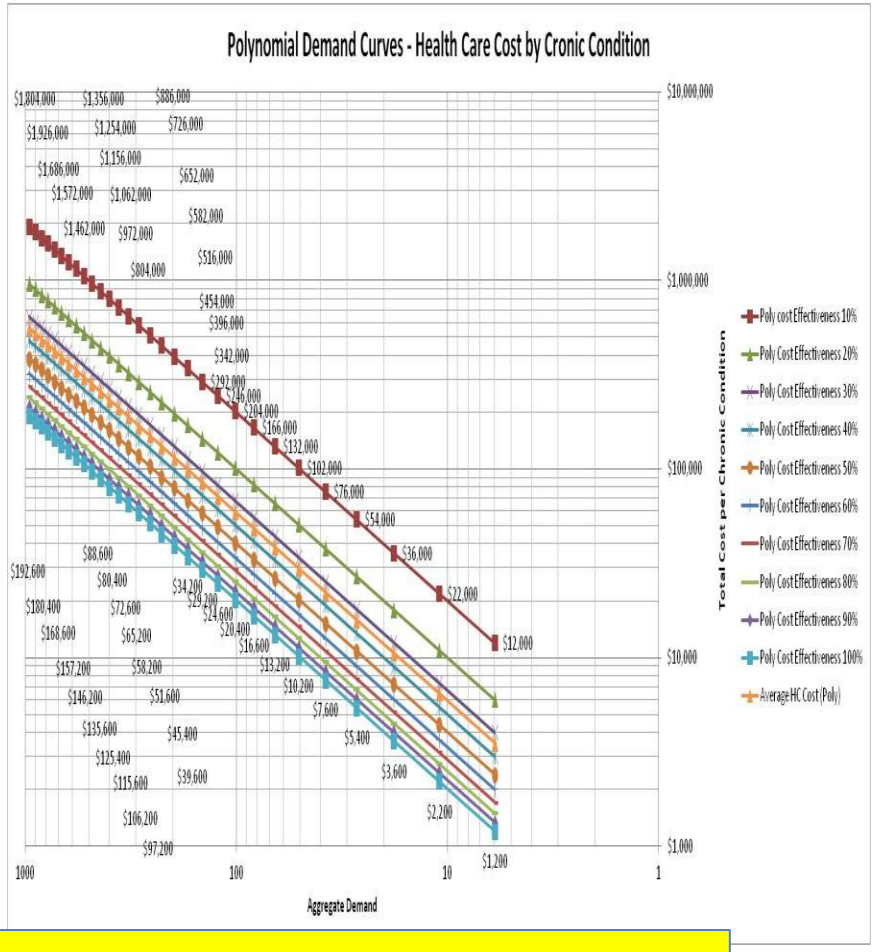
Measuring Effectiveness &QOL





Suppressing Demand





Anticipate 12% reduction of demand, estimate 10% non-compliance

Is Ethical HIT, as Proposed, Ethical

Ethical Principle	Justification	Demonstrable	Score (1-10)
Justice	Informed consent supported by encryption at rest and in transit, key protected	NUC	10
Confidentiality & Trust	Applications LOA3 authentication, along with authorization and encryption used	NUC	10
Transparency for Personal Knowledge	Information received through application is filtered prior to Avatar presentation	TBD	7
Anonymization	CCDA/CHA payload stripped of personal identification	RM+, PHPro	8
Non-maleficence	CQI, Real time feedback, leveraging evidence based guidelines	TBD	7
Beneficence	Avatar supported by Business Intelligence	EMOC (Avatar N/A)	7
Double-effect	AI processes environmental, longitudinal record, presented symptom, evidence, produces most probable outcomes	EMOC (Decision Tree)	7
Professional relationships	Interoperability through the design, secure, social network, care teams, and access to clinician and researcher	RM+ (Dr. Brock NYU)	7
Shared decision making	Patient presents him/her symptom to clinician with knowledge of most probable condition and possible actions	All Applications, built on Extensible Architecture	8
Autonomy	Applications include a decision tree, enables choice	EMOC	8
Informed consumer	Patient makes the decision, feedback loop is push pull, customer satisfaction/effectiveness critical components in Demand Suppression Model	RM+; EMOC	9
Financial viability	Impacts GDP and sustainable	Yes - see model	10

Some Potential Issues

- Market resistance to paradigm shift
  - Possible rejection by patient-provider market segment <= 10% estimate
  - May require high risk pool to cover chronic patient malaise, non compliance
- Application development & port technology limits function/feature robustness
- Measurement methods insufficient at the patient end, and development of longitudinal record corrupted due to inadequate data collection tools & techniques
  - Limiting Avatar functionality and effectiveness
- Extended social network, care team, rejects security methodology
  - PKI managed by remote Encryption Management server
- CCDA-Computerized Health Agent integration with BI proves to be more complex than anticipated
- Care team investment in technology proves burdensome to the Chronic Condition population
- Limited investment halts development

Ethical HIT Prototypes

- EMOC (Promotes cultural change through user engagement)
  - **Uses Real Time Analytics in a Non-Healthcare Environment**
    - **provided as an example of BI use**
    - Input Data & Information – produce output value
  - **Generates excitement**
    - Promotes Value to Customer & Customers' Customer
  - **Enables Your Team (customer and customer's customer - patient and care team)**
    - Connect, Question, Seek Answers, Elaborate, Trust Associates & Verify Results in a Self-Directed Problem Solving Manner
- RM+ (Promotes lower cost, through process efficiency and effectiveness)
  - **Referral Manager Workflow**
    - Connects care teams in secure, collaborative networks for efficient information exchange and clinical performance
  - **Patient Centric Value Chain**
    - Enables workflow automation that streamlines referral tracking and care team management
  - **State of the Art Analytics**
    - Delivers business intelligence (BI) analytics that provide insights for referral process improvement