“An Ethical HIT Capability”

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Ethics in health Information Technology, Problems and Solutions
Sabatini Monatesti, smonatesti@verizon.net
(c) 570-441-2662
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?
"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

Healthcare Data Breaches Continue

Ethical Behavior

US GDP 13%

Broken Encryption

RHIO

Bush - Executive Order 13335 – ONC HIT

Interoperability Critical

ONCHIT - PHIN

Uninsured 45 Million

ADAAA

Wellcare & Sickcare Integration

Uninsured 12 Million

HITEC Act

HISP & BAA (MITM)

Obama - ACA

Cost – Profit Behavior

Prescription Drugs (Price Gouging)

Uninsured Rate

30% > Admin Cost <11%

World GDP 9%

Interoperability Doesn’t Exist

About $12K/Person

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& BAA (MITM)
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

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\(^1\) 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?
Pieces parts!

Ethically
Enabled
Social
Network

Data
Transport

Securely interconnected Computerized Health Agents (CHAs)

- EHRs, PHRs, eForms, Home monitoring devices, etc.
- Develop and deliver continually evolving diagnostic and treatment guidelines
- Interfacing Applications (Models)
- Evolving practice guidelines
- Analytics/Informatics applications
- Research data warehouses

Collect & track patient and treatment information
- Health data & information repositories
- 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

CQI Feedback Loops
- Capture & deliver quality improvement data for analysis
## Extensible Architecture

<table>
<thead>
<tr>
<th>ISO LEVELS</th>
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<tbody>
<tr>
<td>1</td>
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<td>2</td>
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<td>3</td>
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<tr>
<td>4</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Business Architectural Platform/Infrastructure</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Transportation - Automotive/Airline</td>
</tr>
<tr>
<td>- Retail/Wholesale/Restaurant</td>
</tr>
<tr>
<td>- Life-Property-health-Casualty Insurance</td>
</tr>
<tr>
<td>- Industrial/Manufacturing/Import-Export</td>
</tr>
<tr>
<td>- Local/State/federal Government</td>
</tr>
<tr>
<td>- Defense/Federal Systems</td>
</tr>
<tr>
<td>- Real Estate, Banking &amp; Associations</td>
</tr>
<tr>
<td>- Ethical/HIT/Well Care Integration &amp; Interoperability</td>
</tr>
<tr>
<td>- IT/Network Vendors</td>
</tr>
<tr>
<td>- Pharmaceuticals</td>
</tr>
<tr>
<td>- Education/Research</td>
</tr>
<tr>
<td>- Energy</td>
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<tr>
<td>- Aerospace</td>
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</tbody>
</table>

3/16/2018
IEEE ITPC Presentation - ES Enterprises Inc.
Patient Centric Applications

NHDS Inc./RAHN Family

Other Vertical

Healthcare Vertical

Offering

Application

Functions, Features, Options

MyHome

PhPro Consumer

Guideliner

LifeGuide

PhPro Clinician

Referral Manager

CCR/CCD+

Event Infomrer

LifeGuide

Guideliner

Care PathWays+

Care PathWays+

COMS

PACS

Agent 911

Healthy @ Work

Healthy Industrial Vertical

EMOC

Health Information Technology:
Filing Cabinet/Processing Engine/
Document Designer/End-to-End Security
Publisher/Subscriber Node-to-Node/
The Internet of Things

• OK how do we do this?

Using Technology as a Change Agent:
• Self Learning
• Accountable
• See Yourself (Avatar Mirror)
• Promote Evergreen Planning

Search Disparate Data Sources

Incorporate patient-generated Data Wearable devices, etc.

Information Filter (leverage BI)

Internet Of Things

Intelligent App (PhPro)

PHI Mixer (Longitudinal Record)
Network Design

Payload Security

CCDA Path

Internet Cloud

Longitudinal Record (PHI/PHR)

Remote Configuration

Functions similar to a Telephone SS7 SCP

End User Hold Key

LOA3 User

Payload Security

Ethical HIT Application

Microsoft Office

Microsoft Windows OS/TCP/IP

Support Application Encryption – At Rest & In transit

Router & NUC (ISP Provider)

Outlook – SMTP-S/MIME

LOA3 User

Debian Stretch, Intel NUC

End User Hold Key

Payload Security

Ethical HIT Application

Microsoft Office

Microsoft Windows OS/TCP/IP

Support Network Encryption – Conduit In transit

Router & NUC (ISP Provider)

Support Application Encryption – At Rest & In transit

Router & NUC (ISP Provider)

LOA3 User

Debian Stretch, Intel NUC
Proposed Enterprise Connectivity

CCDA Path

CLOUD

IBM eServer™ xSeries

Dual-port Gigabit Ethernet Adapter

Password Synchronization
Consolidated Backup
Auto Failover

Microsoft Windows OS, Outlook,
& Office Apps (Ethical HIT App)

ETHERNET

z/VM Support
TCP/UDP Apps
VTAM/SNA Apps

z/VM Support

Flash Express

Channel Sub Sys
Logical Partitions

IBM Z14 OS

Pervasive Encryption
DB2/IMS & VSAM
Medical PDF attachments
FIPS 140-2 level 4
OSA Ethernet

AI, Genetic Engineering, Advanced Research

IBM eServer™ xSeries

Logical Partitions
z/VM Partition
FICON IO
IP/MAC Network
IPV6 Support
Open Sys Adpt
EHR/EMR/HIE App

AI, Genetic Engineering, Advanced Research
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

Effectiveness = Customer Satisfaction * Quality of Life

Quality of Life = QOL = ((Health Status + Care Process Engagement + Self Management)/3) * Severity of Patient Condition %

\[ y = 0.0138x^4 - 0.0662x^3 + 0.3582x^2 - 0.6383x + 0.3629 \]
\[ R^2 = 0.9713 \]
Suppressing Demand

Anticipate 12% reduction of demand, estimate 10% non-compliance
Is Ethical HIT, as Proposed, Ethical

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