Big Data, Analytics, Privacy and Ethics

Monday, September 15, 2014 • 8:30 am – 12:30 pm
Hilton Chicago, Chicago, IL

Including Keynote Speakers:

Ken Goodman, PhD, FACMI
Director, Bioethics Program, University of Miami

Mike Jennings
Senior Director, Enterprise Architecture, Walgreens

Zoi Kolitsi, PhD
Chief eHealth Policy Advisor, Informatics and Information Security Laboratory, Aristotelean University of Thessaloniki, Greece

Marc Overhage, MD, PhD
Chief Medical Informatics Officer, Siemens Healthcare

Richard Platt, MD
Chair of the Department of Population Medicine, Harvard Pilgrim Health Care Institute; Principal Investigator, PCORI (Patient-Centered Outcomes Research Institute), National Patient Centered Clinical Research Network
8:30 – 8:35 am
Welcoming Comments
Stan Huff, MD
Chair, HL7 Board of Directors

8:35– 9:15 am
Keynote Session 1:
Making Learning Healthcare a Standard(s) Activity
Routinely collected electronic health data can be the foundation of a Learning Health System, one that develops and disseminates evidence about the quality and cost of medical care, the safety of marketed medical products, the comparative effectiveness of preventive care and treatments for established disease, and that supports public health practice. The FDA's Sentinel Initiative and PCORnet, PCORI's National Patient Centered Research Network illustrate some early successes and challenges.

Richard Platt, MD, MsC
Chair of the Department of Population Medicine, Harvard Pilgrim Health Care Institute; Principal Investigator, PCORI (Patient-Centered Outcomes Research Institute), National Patient Centered Clinical Research Network

9:20 – 10:00 am
Keynote Session 2:
Data Protection and Innovation – Can We Strike a Balance?
The healthcare delivery landscape is changing rapidly and significantly to cope with the dynamic change of society and this change is accelerated by the effects of the economic crisis affecting health and social care systems. Fostering a spirit of eHealth innovation for better health, better and safer care for citizens, more efficient and sustainable health and care systems and new business opportunities is the way forward. Still, the risk for innovation stumbling barriers of data protection and security imperatives remains high. A major challenge for governments and stakeholders is to strike the proper balance between benefits and protection for citizens and society. Legislators, regulators, data protection agencies, ethics committees, and innovators must find their common way forward.

Zoi Kolitsi, PhD
Chief eHealth Policy Advisor, Informatics and Information Security Laboratory, Aristotlean University of Thessaloniki, Greece

10:00 – 10:30 am     Break

10:30 – 11:05 am
Keynote Session 3:
JASON: A Man Wearing One Sandal?
Providers, standards organizations, HIT vendors and federal agencies are pursuing healthcare interoperability in order to realize the full value of health information technology. The recent JASON and PCAST reports challenge the course we have charted but most agree they are Pollyannaish. Still our progress toward interoperability has been slower than any of us would like. This talk will explore proposals to speed us forward on our quest.

Marc Overhage, MD, PhD
Chief Medical Informatics Officer, Siemens Healthcare

11:10 – 11:45 am
Keynote Session 4:
How Walgreens Leverages Information to Support Evolving Healthcare Models
This presentation explores how healthcare organizations like Walgreens are preparing for the emerging paradigm of enterprise analytics and how requirements for analytics are shifting from siloed departmental reporting to enterprise-wide demands for clinical and business performance insight. Topics include harnessing big data (structured and unstructured) to improve the holistic view of your organization; examples of improving the quality of patient care while reducing costs by using analytics; and organizational dynamics when implementing enterprise-wide analytics.

Mike Jennings
Senior Director, Enterprise Architecture, Walgreens

11:50 – 12:25 pm
Keynote Session 5:
Interoperability is an Ethical Issue – and Failure to Achieve It is a Betrayal of Our Patients
Platitudes about patient-centered care and learning health systems are hollow and nugatory if we do not do a better job making health information technology serve the needs of patients and clinicians. Meeting this obligation will require better management of IT systems whose developers are bound by precepts of both business ethics and bioethics. These precepts are often in conflict. Key steps in the path forward will be to ensure that IT, data and communication standards support full and bona fide interoperability. History will regard anything less as a cruel trick on the patients for whom we all along said we were toiling.

Ken Goodman, PhD, FACMI
Director, Bioethics Program, University of Miami

12:25 – 12:30 pm     Closing Comments
Charles Jaffe, MD, PhD
CEO, Health Level Seven International
Keynote Session 1: Making Learning Healthcare a Standard(s) Activity

8:35 – 9:15 am

Richard Platt, MD, MsC
Chair of the Department of Population Medicine, Harvard Pilgrim Health Care Institute; Principal Investigator, PCORI (Patient-Centered Outcomes Research Institute), National Patient Centered Clinical Research Network
Dr. Platt is professor and chair of the Harvard Medical School Department of Population Medicine and at the Harvard Pilgrim Health Care Institute. He has extensive experience in developing systems and capabilities for using routinely collected electronic health information to support public health surveillance, medical product safety assessments, comparative effectiveness and outcomes research, and quality improvement programs. Dr. Platt also has experience in performing health system based intervention studies and observational studies using electronic medical record and claims data.

He is principal investigator of the FDA Mini-Sentinel program, which performs post-marketing safety surveillance using the electronic health data from over 175 million people. He is also principal investigator of the coordinating center of PCORI’s National Patient Centered Clinical Research Network, a consortium of 29 networks that will use electronic health data to conduct comparative effectiveness research. He co-leads the coordinating center of the NIH Health Care System Research Collaboratory and leads a CDC Prevention Epicenter. Dr. Platt has been principal investigator of a CDC Center of Excellence in Public Health Informatics, and an AHRQ Center for Education and Research on Therapeutics.

He co-chairs the CER Innovation Collaborative of the IOM Roundtable on Value and Science-Driven Healthcare, and is a member of the American Medical Colleges Advisory Panel on Research.
Slides not available in advance for Richard Platt’s presentation
HL7’s 28th Annual Plenary

Keynote Session 2: Data Protection and Innovation – Can We Strike a Balance?

9:20 – 10:00 am

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Zoi Kolitsi, PhD
Chief eHealth Policy Advisor, Informatics and Information Security Laboratory, Aristotelean University of Thessaloniki, Greece
Zoi Kolitsi, is an eHealth strategist and is currently an affiliated member of the Information Security Laboratory of the Aristotelian University of Thessaloniki. She is a senior advisor with the Ministry of Health and member of the national eHealth Strategy Group. Her current activities also include leading the Interoperability Assets WP in EXPAND, legal and regulatory issues work in the epSOS LSP and in the eHealth Governance Initiative. She is also the chair of the national Sectoral Technical Committee for eHealth of ELOT (TET 14/1) and has led the CALLIOPE Thematic Network for EU eHealth Interoperability.
Data Protection and Innovation
Can we strike a balance?

Zoi Kolitsi
Informatics and Information Security Laboratory
Aristotelian University of Thessaloniki, Greece

HL7 International 28th Annual Plenary & Working Group Meeting, Chicago, 14-19 Sept, 2014
Health care is special...

- Health systems linked to culture and social policies
- In Europe, subsidiarity principle
  - Co-operation on public health matters BUT
  - No harmonization of MS health care legislation
  - Member States have full control on how they organize their systems

**HOWEVER**

- Substantial variations between national health care systems, but also similar challenges are faced and
- Substantial similarities in political ambitions to reform health care as well as in the challenges to reach these goals
Health Data is special...

Data from SPECIAL EUROBAROMETER 359 Report, *Attitudes on Data Protection and Electronic Identity in the European Union*, June 2011

HL7 International 28th Annual Plenary &Working Group Meeting, Chicago, 14-19 Sept, 2014
Health Data requires a high level of protection...

- Data Protection a critical matter for data processing in eHealth
  - Legal basis for data processing is necessary
  - Ethical, regulatory and human rights instruments are also relevant.
- Large Diversity across countries
  - Challenging when crossing national and professional boundaries

Need to strike a balance between achieving a consistent level of data protection and rights, removing obstacles and cutting red tape.
Different purpose, different needs...

For care purposes
• information sharing within the same context is done on a “need to share” basis within a defined healthcare team
Health and medical institutions are trusted ...

Data from SPECIAL EUROBAROMETER 359 Report, *Attitudes on Data Protection and Electronic Identity in the European Union*, June 2011

HL7 International 28th Annual Plenary &Working Group Meeting, Chicago, 14-19 Sept, 2014
Beyond team based health care

- wide variety of potential “secondary” use of data open to healthcare professionals outside the team, social care providers, insurers, technical staff, researchers, and others
- Data re-use made possible in other sectors but major challenges remain in eHealth
  
  * * * Semantic Interoperability and legal barriers
Mobile applications in health

- Extramural care and remote monitoring, patients on the move
- Extensive use of smart phones and proliferation of apps
- User identifiable data on location and access to info on the web
Big Data Analytics

- Potential to create new knowledge in research and enormous benefits for governments to improve health service delivery and detect fraud.
- A market eager to exploit business use cases leveraging such potential
- No real controls and limited citizen knowledge of the risks or informed consent
- Need for policies and laws to protect privacy

✔ Big data tools can alter the balance of power between government and citizen.
✔ Big data tools can reveal intimate personal details.
✔ Big data tools could lead to discriminatory outcomes.

Big Data: Seizing Opportunities, preserving values, Executive Office of the President, May 2014
Security and Privacy Challenges

Source: Top Ten Big Data Security and Privacy Challenges, Big Data Working Group, Cloud Security Alliance, April 2013
Key messages from international collaboration

- epSOS - a Large Scale Pilot for data sharing across borders in Europe
  - Trillium Bridge investigating the transatlantic dimension
- CALLIOPE – a Thematic Network for eHealth interoperability, delivered the eHealth Interoperability Roadmap
- eHGI – eHealth Governance Initiative supporting the policy co-ordination process
- eSENS – a Large scale pilot for cross sectoral interoperability
Working together to tackle common challenges

- **Policy level:** the Article 14* eHealth Network
  - members are high level policy officials of national health administrations
- **Strategy Level:** Support mechanisms and Joint actions to consolidate national experience and recommendations from pilots
- **Implementation level:** Common large scale pilots, Networks, Stakeholder engagement

*of Directive 2011/24
Address simultaneously all levels of interoperability in a step by step approach.

CALLIOPE Interoperability Roadmap, December 2010

HL7 International 28th Annual Plenary &Working Group Meeting, Chicago, 14-19 Sept, 2014
Critical Issues for eHealth

- Establishing maintaining and safeguarding trust in the EU/international context
- Authorizations to access data, including patient consent
- Specific identification challenges
- Privacy by design
- Accountability, traceability and audit
- Creating and maintaining convergence
- Patient Access to own health data - opportunities and limitations
Legal Interoperability Agreements

The epSOS Approach*

- In compliance with EU and National Legislation
- Addressing diversity

- Pre-requisite: a solid governance framework

*NOTE: Positively considered by the DPAs (WP29 working document on epSOS)
From Interoperability Agreements to Legal Action

- Recommendations form pilots
- Policy development
- Adoption of guidelines
- Voluntary national action for cross border interoperability
Tackle horizontal legal issues for a stepwise approach

**Horizontal issues**

- establishing and safeguarding trust
- Common policies, measures (e.g. NCPeH, circle of trust, eID for eHealth, secondary use of data)
- Co-ordination and Collaborative Governance (agreements, monitoring, arbitration)

**Use case specific issues**

- Seamless security and trust across all players of the value chain
- Use case specific regulations (risk adjusted access policies, medicines, reimbursement, clinical trials...)
- Organizational, viability and sustainability aspects
... and yes, eHealth is special!

- Cross sectoral eID and use of eSignatures in eHealth may be considered (identification and authentication) but authorization is a complex eHealth issue
- Semantic interoperability aspects are far more complex and involved
- Engagement of stakeholders –especially end users and industry is a must
- A good level of collaborative governance is a prerequisite
LEGISLATION
Modernization of Data Protection Legislation

IN EUROPE

- Data Protection
  - A (General) a EU Regulation on the protection of individuals with regard to the processing of personal data and on the free movement of such data
  - To be applied and enforced **nationally**
  - In process of approval, to succeed the Data Protection Directive
- Electronic identification and trust services
  - EU Regulation on electronic identification and trust services for electronic transactions in the internal market, published July 2014
- Standardization
  - the European Standardization Regulation which impacts primarily on the adoption of technical specifications in the domain of ICT, October 2012

- Advance the Consumer Privacy Bill of Rights.
- Pass national data breach legislation.
- ...........
- Amend the Electronic Communications Privacy Act.

Big Data: Seizing Opportunities, preserving values, Executive Office of the President, May 2014
Three main Innovations in the EU Data Protection Reform (in process)

- **One continent, one law**: single, pan-European law for data protection, Companies will deal with one law, not 28.

- **One-stop-shop** for businesses: companies will only have to deal with one single supervisory authority

- **The same rules for all companies – regardless of their establishment**: companies based outside of Europe will have to apply the same rules. Companies with strong procedures for protecting personal data will have a competitive advantage on a global scale at a time when the issue is becoming increasingly sensitive.

The benefits are estimated at €2.3 billion per year.

- Extend privacy protections to non-US persons.

Big Data: Seizing Opportunities, preserving values, Executive Office of the President, May 2014
Highlights

• Protection of personal data **balanced** with other fundamental rights, in accordance with the principle of proportionality.
• Protection of individuals should be **technologically neutral**
• **Clarity** on “person identifiable data”
• **Citizens in control** – provisions for information and freely-given, specific and informed consent, provided unambiguously by any appropriate method
• **Genetic data** is personal data
• **Impact** analysis
• Ensuring **appropriate** security levels
• The right to be forgotten – **adjusted** to societal needs
• **Data Portability**
• **Health specific** provisions!
Specifically for Big Data Analytics

- **Accountability** and social responsibility a global competitive advantage - Impact Analysis and risk adjusted security.
- Promotes **honest communication and unambiguous information** on the impacts to personal privacy from big data and analytics in each and every situation.
- Emergence of the **informed consumer** that can weigh the benefits and the risks.
- The state provides **control, enforcement and redress mechanisms**.
- Strict and austere **consequences for breaches**.
Specifically for eHealth (in discussion)

- Processing of personal data for health-related purposes
- Processing for purposes of social protection*
- Processing of personal data for archiving purposes in the public interest *
- Processing of personal data for statistical and scientific purposes*

* Member State law /the controller shall provide for specific and suitable measures to safeguard the rights and freedoms of the data subject...
GOVERNANCE
The case of re-using identifiable health data

- Providing specific, informed prior consent is not possible and per case consent has a huge organizational overhead
- Re-using data without citizens being informed is out of consideration
  - MS deciding for their own? Obstacles to research relying on international evidence.
  - A common policy on controllers responsibilities?
    - Common principles, need for safeguards and measures
    - National level derogations (for reducing burden)
In addition to legislation

- **Layered Governance - International (Union), national, organization**
- **Collaborative**
  - Together with competence centers, stakeholders and experts
  - Define measures and safeguards
  - Propose methods and solutions
- **Co-ordination**
  - at the political/policy level (in Europe the eHealth Network)
  - Adopt guidelines
  - Voluntarily evolve national regulatory framework

- Trusted eHealth National Contact Points
- Patient access to Electronic Health Records and health data portability
- Electronic Identification for eHealth
- Secondary use of Medical Data
- Implementation of legal interoperability (Guidelines)
- Implementation of data protection Regulation in eHealth
Thank you!

e-mail: kolitsi@vivodinet.gr
Keynote Session 3: JASON: A Man Wearing One Sandal?

10:30 – 11:05 am

Marc Overhage, MD, PhD
Chief Medical Informatics Officer, Siemens Healthcare
Dr. Overhage is the Chief Medical Informatics Officer for Siemens Healthcare. Prior to joining Siemens he was the founding Chief Executive Officer of the Indiana Health Information Exchange and was Director of Medical Informatics at the Regenstrief Institute, Inc., and a Sam Regenstrief Professor of Medical Informatics at the Indiana University School of Medicine.

He has spent over 25 years developing and implementing scientific and clinical systems and evaluating their value. With his colleagues from the Regenstrief Institute, he created a community wide electronic medical record (called the Indiana Network for Patient Care) containing data from many sources including laboratories, pharmacies and hospitals in central Indiana. The system currently connects nearly all of acute care hospitals and 22,000 physicians in central Indiana and includes inpatient and outpatient encounter data, laboratory results, immunization data and other selected data. In order to create a sustainable financial model, he helped create the Indiana Health Information Exchange, a not-for-profit corporation. In addition Dr. Overhage has developed and evaluated clinical decision support including inpatient and outpatient computerized physician order entry and the underlying knowledge bases to support them. He practiced general internal medicine for over 20 years including the ambulatory, inpatient and emergency care settings.

Over the last decade, Dr Overhage has played a significant regional and national leadership role in advancing the policy, standards, financing and implementation of health information exchange. He served on the National Committee for Vital and Health Statistics and the Health Information Technology Standards Committee as well as serving on the Board of Directors of the National Quality Form and being engaged in a number of national healthcare initiatives.
Jason: a man with one sandal

J. Marc Overhage, MD, PhD
Chief Medical Information Officer
Siemens Health Services
The JASON Report

• Sponsored by AHRQ in collaboration with ONC and the Robert Wood Johnson Foundation

• JASON is an independent scientific group that provides consulting services to the US government on matters of science and technology. It was established in 1959.
Who is Jason?

• The name "JASON" is sometimes explained as an acronym, standing either for "July August September October November", the months in which the group would typically meet; or, tongue in cheek, for "Junior Achiever, Somewhat Older Now". However, neither explanation is correct; in fact, the name is not an acronym at all. It is a reference to Jason, a character from Greek mythology. The wife of one of the founders (Mildred Goldberger) thought the name given by the defense department, Project Sunrise, was unimaginative and suggested the group be named for a hero and his search.
JASON Study Charge

• How can complex data handling techniques and Internet-based technologies be applied to health care to promote the development of real-time integrated datasets at a scale seen in other industries?

• How can the various users of health data in the clinical research and public health communities be presented with tailored and highly specific data views in near real time based on routinely collected health data?

• As health data grows from megabits to gigabits per individual, what fine-grained analytics should be made available to patients and health care providers to guide health care decisions?

• What fundamental data management capabilities are needed to support potential future requirements in an open-ended manner?

• What are the national security consequences of not addressing comprehensive health data opportunities in clinical research and public health?
The JASON Report Key Points

The JASON report concludes that MU Stages 1 and 2 have not achieved meaningful interoperability “in any practical sense” for clinical care, research, or patient access due to the lack of a comprehensive nationwide architecture for health information exchange.

They point to the lack of an architecture supporting standardized APIs, as well as EHR vendor technology and business practices, as structural impediments to achieving interoperability.

They recommend an urgent focus on creating a “unifying software architecture” to “migrate” data from these legacy systems to a new centrally orchestrated architecture to better serve clinical care, research, and patient uses.

This architecture would be based on the use of “public” APIs for access to clinical documents and discrete data from EHRs, coupled with enablement of increased consumer control of how data is used.
Interoperability Trends

• There has been much more success to date in vertical interoperability rather than horizontal interoperability

• Vertical interoperability: integrating different types of clinical transactions or functions
  – EHR systems connect relatively easily with Surescripts, labs, radiology systems, and medical devices

• Horizontal interoperability: integrating sources of the same type of clinical transactions or functions
  – Surescripts has created horizontal interoperability across major pharmacies
    • Downside has been pricing structure that has been a barrier to hospital access to medication history
  – Lab market is highly fragmented and no industry actor has emerged to dominate or standardize this market
    • Large commercial labs make up ~25% of market, with remainder provided by hospital labs
  – Most difficult to achieve has been EHRs communicating with each other
    • Lack of user demand for cross-EHR interoperability
    • EHR vendors trying to create stickiness in their products
Office-Based Physicians’ Electronic Health Information Exchange (HIE) With Other Providers, By Organizational Affiliation, 2013.

Furukawa M F et al. Health Aff, 2014
Directed Exchange

- Indiana: 827,483
- Colorado: 138,422
- New York: 98,976
- Minnesota: 48,655
- Vermont: 35,359
- Delaware: 29,627
- Washington: 28,439
- Michigan: 3,701
- Maryland: 2,482
- Ohio: 889,700
- Rhode Island: 1,680,124
- California: 3,322,812
- Alaska: 5,011,816
- Utah: 14,532,368

Tripathi, HITPC, January 2013
JASON Architecture Core Principles

• The patient owns his or her data
• The patient participates in the management of his or her data
• Be agnostic as to the type, scale, platform, and storage location of the data
• Use published APIs and open standards, interfaces and protocols
• Encrypt data at rest and in transit
• Separate key management from data management
• Include metadata, context, and provenance of the data
• Represent the data as atomic data with associated metadata
• Follow the robustness principle: “Be liberal in what you accept, and conservative in what you send.”
• Provides a migration path from legacy EHR systems
## JASON Example Architecture

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<th>Stovepipe Legacy Systems</th>
<th>User Interface Apps</th>
<th>Middleware Apps</th>
<th>Semantic and Language Translation</th>
<th>Search and Index Functionality</th>
<th>&quot;chart/record&quot; data</th>
<th>&quot;atomic&quot; data w/ metadata</th>
<th>Crypto Layer</th>
<th>Key and Certificate Management</th>
<th>Published API</th>
<th>Data Storage (logical)</th>
<th>Data Transport (logical)</th>
<th>Data Storage (physical)</th>
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- **User Interface Apps**
- **Middleware Apps**
- **Semantics and Language Translation**
- **Search and Index Functionality**
- **"chart/record" data**
- **"atomic" data w/ metadata**
- **Data Storage (logical)**
- **Data Transport (logical)**
- **Data Storage (physical)**
- **Data Transport (physical)**
- **Identity, Authentication, Authorization**
- **Patient Privacy Bundle Management**
- **Key and Certificate Management**
JASON Example Architecture
(With proposed mapping to standards)

User Interface Apps

Middleware Apps

Semantics and Language Translation

FHIR Profiles

Search and Index Functionality

“chart/record” data CCDA/XDS

“atomic” data & metadata FHIR

Crypto Layer (leverage existing approaches)

Published API

Stovepipe Legacy Systems

Identity, Authentication, Authorization

Patient Privacy Bundle Management

Key and Certificate Management

Data Storage (logical)

Data Transport (logical)

Data Storage (physical)

Data Transport (physical)
Are Meaningful Use Stage 2 certified EHRs interoperable? Findings from the SMART Collaborative

John D D’Amore,1,2 Joshua C Mandel,3,4 David A Kreda,5 Ashley Swam,1 George A Koromia,1 Sumesh Sundareswaran,1 Liora Alschuler,1 Robert J Dittus,1 Kenneth D Mandl,3,4,6 Isaac S Kohane,3,6 Rachel B Ramoni6,7

ABSTRACT
Background and objective Upgrades to electronic health record (EHR) systems scheduled to be introduced in the USA in 2014 will advance document interoperability between care providers. Specifically, the second stage of the federal incentive program for EHR adoption, known as Meaningful Use, requires use of the Consolidated Clinical Document Architecture (C-CDA) for document exchange. In an effort to examine and improve C-CDA based exchange, the SMART (Substitutable Medical Applications and Reusable Technology) C-CDA Collaborative brought together a group of certified EHR and other health information technology vendors.

In our study, we apply the concept of semantic interoperability to data within Consolidated CDA and C-CDA documents to produce to satisfy federal regulation. We study core variation as classification to examine if reliable semantic variation is possible.

EHR adoption and Meaningful Use EHR use in the USA has risen with certified EHRs now used by nearly 95% of hospitals and 85% of office-based physicians.
Summary of CCDA Challenges (I)

• Wide implementation variation across EHR vendors
• Current standards and implementation guides allow too much variability
• Summary documents is left up to EHR vendor discretion, too much information shared
  – Need pertinent clinical summary of a patient or most relevant data
  – Stage 2 requires content for 17 different data elements, no instructions for when an element is not present
    • NullFlavor fields are available, but examples and implementation guidance is lacking
Summary of CCDA Challenges (II)

- Certification focuses on the creation and transport of CCDA, not intake
  - Testing needed for appropriate conformance to common vocabularies (e.g. SNOMED, LOINC, RxNorm)
  - Variation in how no known medication intolerances and no known environmental or substance allergies are handled
  - CCDA does not handle data versioning; therefore, data correction in the case of errors requires manual intervention
  - Many CCDA instances have more specificity in the narrative section than in the discrete data section

8/11/2014
Real Barriers to Interoperability

• Maintaining privacy
• Misaligned incentives
• Competing priorities
• Same old problems
  – Semantic variations
  – Patient, provider and location matching
• Missing events model
Keynote Session 4: How Walgreens Leverages Information to Support Evolving Healthcare Models

11:10 – 11:45 am

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Mike Jennings
Senior Director, Enterprise Architecture, Walgreens
Mike Jennings is a recognized industry expert in enterprise architecture and information management. He has more than twenty five years of information management experience in various industries. Mike speaks frequently on enterprise architecture and information management concepts and practices at major industry conferences. He is a co-author of the book “Universal Meta Data Models” (2004) and a contributing author to the books “Building and Managing the Meta Data Repository” (2000) and “The DAMA Guide to the Data Management Body of Knowledge - DMBOK” (2009). Mike was recognized with the 2013 DAMA International Professional Achievement Award and as one of Information Management Magazine’s 25 Top Information Managers for 2012.
How Walgreens Leverages Information to Support Evolving Healthcare Models

15 September 2014
Mike Jennings
Walgreens is the nation’s largest drugstore chain, with fiscal 2013 sales of $72.2 billion. The Company has 240,000 employees.

- Walgreens filled 821 million prescriptions in fiscal 2013.
- Walgreens serves 6.3 millions customers daily.
- 120 million active Balance® Rewards members.
- Walgreens has more than 8,582 locations, including our stores, worksite health centers, infusion and respiratory service facilities, specialty pharmacy, and mail service facilities.
- Fast Company ranked Walgreens ranked as the 7th most innovative health care company for its leadership in redefining the role of the pharmacy. The magazine cited new mobile app features that help patients manage their medications as well as the company's partnerships with the CDC and the Department of Health and Human Services to expand in-store HIV testing, which created a new standard for the patient-pharmacy relationship.
Walgreens Purpose and Vision

Our Purpose...
To help people get, stay and live well

Our Vision...
To be the first choice in healthy and daily living for everyone in America – and beyond
Creating a Unique Experience by...

- Delivering Extraordinary Customer Care
- Offering the Right Products & Solutions
- Meeting the Needs of Local Communities
Advancing Community Pharmacy
Expanding the Offering at Healthcare Clinics...

- Walk-Ins Welcome & Appointments Available
- Open 7 Days & Weeknights, Too
- Most Insurance Accepted
- Treatment For Patients 18 Months & Older
- Board-Certified Family Nurse Practitioners
- Integrated Pharmacy Experience

prevention & wellness
- vaccines
- physicals & wellness visits
- health screenings & testing

treatment
- illness, aches & pains
- minor injuries
- skin conditions

monitoring & management
- ongoing health conditions
- medications & treatments
Providing Comprehensive Care...
...And a Differentiated Experience.
Building Strategic Partnerships...

Johns Hopkins Hospital

Northwestern Memorial Hospital
Establishing an Efficient Global Platform...
US Healthcare is Changing Rapidly

- Primary Care Shortage
- Retailization of Healthcare
- New Incentive Models Requiring:
  - Teamwork and Partnership
  - Exchange of Information and Intent
- Consumerism: Increased Choice and Responsibility
Empowered Consumers Will Need Help

US Healthcare has some significant avoidable problems.

- Poor Medication Adherence, $300B Cost
- Lack of Incentives For Prevention and Wellness
  - Immunizations
  - Health Testing / Screenings
- ER Overuse, 1/3 Avoidable, $18B Cost
- Poor Chronic Management

Much of this is about *behavioral change*.
What Drives Behavior Change?

**Motivation**
- Pleasure / Pain
- Hope / Fear
- Social Acceptance / Rejection

**Trigger**
- Signal
- Spark
- Facilitation

**Ability**
- Simplicity
- Convenience
- Cost
The Retail Industry Does This Well

**Content**
- Advertising
- Brand Halo / Product Prestige
- Gifting Feeling; Good by Giving

**Trigger**
- Rewards Program
- Personalized Marketing
- Multichannel Campaigns
- Personal Shoppers

**Engagement Engine**

**CRM**

**Ability**
- Convenient Locations
- Rich Digital Experience
- Call Centers
- Localized Assortment

**Channel**
Healthcare Should Be Better Than Retail

**Identifiable** customers
**Evidence-based** content

- Medication Reminders
- Targeted Messaging
- Immunization Reminders
- Care Gap Alerts
- Threshold Alerts
- Appointment Reminders
- Individualized Education
- New to Therapy Campaigns
- Caregiver Messaging
- Coaching / Reinforcement
- Social Content

**Many Barriers:**
- Complexity
- Channel Economics
- Available Time

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Walgreens Engagement Model

Product Recommendation

Healthcare Recommendation

Content

Omnichannel
The Walgreens Engagement Engine

11 MILLION
CUSTOMER VISITS DAILY
6 MILLION STORE
3 MILLION CALLS
2 MILLION DIGITAL

120 MILLION
REWARDS PROGRAM MEMBERS
ACTIVATED IN 18 MONTHS

2.1 MILLION
PRESCRIPTIONS FILLED PER DAY

8.5 MILLION
IMMUNIZATIONS PERFORMED ANNUALLY

2/3 OF THE
US POPULATION
LIVES WITHIN
3 MILES
OF A WALGREENS

70,000
HEALTHCARE PROVIDERS

248,000
WALGREENS TEAM MEMBERS

8200 COMMUNITY PHARMACIES

ONE EVERY SECOND
PRESCRIPTION REFILL REQUESTS
FROM MOBILE “REFILL BY SCAN”

27,000
PHARMACISTS

700 RETAIL AND WORKSITE CLINICS

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Rewarding Healthy Behavior

We are pointing the engine towards healthy decisions…

… and can help our partners do the same.
Teaming to Improve Outcomes

- Clinical Content Exchange
- Bi-Directional Referrals
- Adherence
- Care Plan Reminders

- Clinical Content Exchange
- Discharge Follow-up
- Adherence
- Care Plan Reminders

- Targeted Messaging
- Out-Of-Network Alerting

- Targeted Messaging
- Clinical Trial Availability
- New to Therapy Content

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Global Reach Provides New Insights

CPG Insights

Pharma Insights

Supply Chain Analytics

Supply Chain Analytics

Global Reach Provides New Insights
Analytics: Next Areas of Focus

Integrating and Expanding The Information Base

- Consumer Directed Health Record Custodianship / Exchange
- Wellness Index & Predictive Modeling
- Consumer / Medical Device Signal Data Integration
- Threshold / Event-Based Intervention As A Service

Partnership / Ecosystem Analytics As A Service

- Extended Care Gap Identification
- Population Health & Predictive Modeling
- Global Biosurveillance for Government Disease Control / Pharma

Providing Insight At Point of Service

- Real-time Decision Support for Internal Practitioners
Future State Analytics
Information into Insights into Action

Understand patient behavior

Personalize patient experience

Leverage data sources & capabilities

Improve speed to market of patient services through trusted data

Global analytics

Enhanced analytics capabilities

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THANK YOU!
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Michael Jennings is a recognized industry expert in enterprise architecture and information management with more than twenty-five years of experience in various industries. Mike speaks frequently on enterprise architecture and information management concepts and practices at major industry conferences.


Mike was recognized with the 2013 DAMA International Professional Achievement Award and as one of Information Management Magazine’s 25 Top Information Managers for 2012.

He currently serves as VP of Programs for the Wisconsin DAMA Chapter and as VP of Operations for DAMA International.
HL7’s 28th Annual Plenary

Keynote Session 5: Interoperability is an Ethical Issue – and Failure to Achieve It is a Betrayal of Our Patients

11:50 – 12:25 pm

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Ken Goodman, PhD, FACMI
Director, Bioethics Program, University of Miami
Kenneth W. Goodman is founder and director of the University of Miami Bioethics Program and its Pan American Bioethics Initiative and co-director of the university’s Ethics Programs, including its Business Ethics Program. The Ethics Programs have been designated a World Health Organization Collaborating Center in Ethics and Global Health Policy, one of six in the world.

Dr. Goodman is a Professor of Medicine at the University of Miami with appointments in the Department of Philosophy, Department of Health Informatics, Department of Public Health Sciences, Department of Electrical and Computer Engineering, School of Nursing and Health Studies and Department of Anesthesiology. He is responsible for ethics consult services for the University of Miami Miller School of Medicine Hospital System and Miami-Dade County’s Jackson Health System, or some 2,500 beds.

He is past chair of the Ethics Committee of AMIA (American Medical Informatics Association), for which he co-founded the Ethical, Legal and Social Issues Working Group. He is a Fellow of the American College of Medical Informatics, the only philosopher or ethicist to be elected. He is director of the Florida Bioethics Network.

Dr. Goodman’s research has emphasized issues in health information technology. He is writing a book about ethics and informatics for Cambridge University Press. He has edited a book on the Terri Schiavo case (Oxford), published a book about ethics and evidence-based medicine (Cambridge), co-authored a book of case studies in ethics and health computing (Springer-Verlag) and co-authored another volume of case studies, in ethics in public health (American Public Health Association). He has also co-authored a book on artificial intelligence, edited a book on ethics and medical computing, co-edited a volume on artificial intelligence, and published and presented numerous papers in bioethics, the philosophy of science, and computing.

Current funded work includes directorship of the ethics component of the University of Miami’s Clinical and Translational Science Institute and a project to develop an advance directive app for the Alpha-1 Foundation. He recently completed work on an NIH/Fogarty International Center grant to help expand research ethics education around the Americas.
Interoperability is an Ethical Issue – and Failure to Achieve it is a Betrayal of Our Patients

Health Level Seven International
28th Annual Plenary & Working Group Meeting

Chicago, September 15, 2014

Kenneth W. Goodman, Ph.D., FACMI
University of Miami Bioethics Program
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“Melodies cannot be written.”

Isidore of Seville (c. 560-636)
Practical Small Examples

1. a. Fetal monitor output
   b. EHR input
   c. $a \parallel b$

2. Code status and advance directives
Ethics as Prohibitive

Often precautionary:
• Stop (e.g., reproductive cloning)
• Postpone (e.g., genetic engineering)
• Slow down (e.g., neuroethics)
Ethics as Prescriptive

Identification of duties:

• Reduce disparities
• Establish, foster and raise minimum standards
• Protect rights
“Progressive Caution”

Health information technology (HIT) introduces tools whose very availability entails an obligation to develop, adapt, use them more widely.
Ethics and Digital Science

• Software engineering
• Data sources, consent and privacy
• Evidence-based standards
• Patient-centered throughout
• Interoperability as necessary condition
Software Engineering

- Version control
- Provenance, attestation, version control
- Pareidolia and decision support
- Trust
Data, Sources, Consent, Privacy

• Privacy vs. other values
• Data sources, consent and privacy
• Applications
• Implied consent?
Collapse of a Distinction

Clinical data >
Research data >
Surveillance data >

*Undermining the myth of “secondary use,” especially for public health*
“Information Free-Riders”

- Emphasize privacy over public health
- Risk little if anything
- Benefit from others’ contributions of information
Analogues

- Vaccine refusers
- Organ donation refusers
- Infrastructure support refusers
Applications

• Decision support
• Exception management
• Anomaly detection > “incidental findings”
• Monitoring, surveillance, research
Learning Health Systems

- Require data interchange …
- Which is assumed by patients …
- And needed for clinical practice, public health and translational science
Practical Big Example

*(Recall practical small examples)*

- “File drawer problem”
- If goal of a LHS is to metabolize Big Data,
- Then bona fide interoperability is a corrective to reliance on the flawed publication record
Interoperability Ethics

• If interoperability improves outcomes, it becomes a duty to achieve it
• If it reduces cost and increases efficiency …
• If it fosters trust in our systems …
Interoperability is an Ethical Issue – and Failure to Achieve it is a Betrayal of Our Patients

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