26th Annual Plenary Meeting: HL7 in the Era of Patient Empowerment

Monday, September 10, 2012 • 8:30 am – 12:30 pm
Hyatt Regency Baltimore
Baltimore, MD

Including Keynote Speakers:

Leslie Kelly Hall
Senior Vice President, Healthwise

Lee Rainie
Director, Pew Research Center’s Internet & American Life Project

Elaine Blechman, PhD
Professor Emerita, University of Colorado-Boulder; President, Prosocial Applications
8:30 – 8:45 a.m.  
**Welcoming Comments**  
*Don Mon, PhD, Chair, HL7 Board of Directors*

8:45 – 9:15 a.m.  
**Keynote Session 1: Engaging Patients with Standards**  
Topics covered will include how the HIT standards professional can transform healthcare by:  
- Enabling patients to be informed and informing  
- Bridging the legacy and innovative technologies  
- Harmonizing EHR and patient facing system interactions  
- Maximizing the data to improve quality  

*Leslie Kelly Hall, Senior Vice President, Healthwise*

9:15 – 9:50 a.m.  
**Keynote Session 2: The Rise of e-Patients**  
Three technology revolutions in the last generation have changed the way patients care for themselves and interact with doctors and peers:  
1. The internet/broadband revolution  
2. The mobile revolution  
3. The social networks revolution  

Lee Rainie will describe how patients and caregivers use these technologies to inform themselves, deal with medical providers, and share their stories with fellow patients and their loved ones.  

*Lee Rainie, Director, Pew Research Center's Internet & American Life Project, and formerly the managing editor of the news magazine U.S. News & World Report*

9:50 – 10:25 a.m.  
**Keynote Session 3: The Consumer Empowerment**  
Policy makers, professionals and technologists paradoxically believe that homogeneous health information technology standards can empower clinically heterogeneous healthcare consumers. This paradox underlies a 2004 presidential order for a Nationwide Health Information Network and a National Coordinator of Health Information Technology. Since then, HL7, HITSP, IHE, and the Standards & Interoperability Framework have acted on this paradox, developing consumer standards for patient portals, personal health records (PHRs), care coordination, transitions of care, data segmentation, telehealth, mobile devices and direct encrypted email. Evidence that few consumers use free portals threatens belief in the paradox, development of consumer standards and citizen support for healthcare reform.  

The consumer empowerment paradox appears to accurately represent longstanding, top-down vs. bottom-up contradictions in health care delivery, yet needs empirical testing. Paradox testing, in turn, requires a logic model that traces paths from keystone standards for clinical summary exchange to
the potential empowerment of diverse consumers and the frustration of diverse providers. Test results are likely to reveal gaps in policy and standards that obstruct meaningful health IT use among consumers and providers alike.

Elaine A. Blechman, PhD, Professor Emerita, University of Colorado-Boulder and President, Prosocial Applications

10:25 – 10:50 a.m. Break

10:50 – 12:20 p.m. Panel discussion featuring presentations from different stakeholders in the mobile health space on how they view the future of mobile health and HL7’s potential role in this evolving arena
Moderated by Doug Fridsma, MD, PhD, Director, Office of Standards and Interoperability, Office of the National Coordinator for Health IT

- 10:55-11:10 Chuck Parker, Executive Director, Continua Health Alliance
- 11:10-11:25 Christoph Lehmann, MD, Professor of Pediatrics and Biomedical Informatics, Vanderbilt University, will discuss empowering families of children
- 11:25-11:40 Jim St. Clair, Senior Director, Interoperability and Standards, HIMSS
- 11:40-11:55 Lonnie Smith, Policy Analyst, U.S. Food and Drug Administration (FDA), will discuss mobile applications of SPL
- 11:55-12:10 Heather Llewelyn Grain, Standards Australia
- 12:10-12:20 Questions and answers for panelists

12:20 – 12:30 p.m. Closing Comments and a vision for HL7’s Future
Charles Jaffe, MD, PhD, CEO, Health Level Seven International
HL7’s 26th Annual Plenary

Keynote Session 1: Engaging Patients with Standards

8:45 – 9:15 am

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Leslie Kelly Hall
Senior Vice President, Healthwise
Leslie Kelly Hall’s experience as a former hospital administrator and her vision as a consumer/patient advocate fuel the successful integration of patient engagement and shared decision making in Healthwise products. As senior vice president of policy, Hall guides policy efforts for Heath Information Technology (HIT) and patient engagement.

She is widely recognized as a leader in health care information technology. Hall was appointed by Health and Human Services (HHS) Secretary Kathleen Sebelius to serve on several Federal Advisory Committees:

- Health Information Technology Standards Committee
  - Patient Engagement Power Team: Chair
- Health Information Technology Policy Committee
  - Meaningful Use Subcommittee
  - Patient Engagement Power Team: Co-Chair
  - Care Coordination: Co-Chair

In addition to her work around patient engagement, Hall’s HHS committee work gives her in-depth knowledge of Meaningful Use requirements. She is a frequent presenter at federal and industry summits, including the 2012 White House Patient Access Summit, the Post-Acute Health IT Summit, and the HL7 Plenary Session on Patient Engagement.

Prior to her current position, Hall was senior vice president of products at Healthwise, where she was responsible for bringing new products to market and managing legacy product success. Before joining Healthwise, Hall held senior-level information technology and marketing management positions in health care organizations, including Saint Alphonsus Regional Medical Center in Boise and Prodata Corporation (now Comsys).

Her achievements in the provider market have made a significant impact on patients and physicians and on the health care system in the state of Idaho. In 1996 she created Idaho’s first physician portal, and was the driving force behind the development of innovative IT environment implementing systems. These systems resulted in lower costs, increased productivity, and dramatic improvements in patient care and safety.
Leslie Kelly Hall
lkellyhall@healthwise.org
The early years....
The mess starts ....
Interface years....
Interoperability
The Web Smart 50

CALL AN END TO THAT HEAD-SHAKING and tut-tutting at the mere mention of the Web. The bust is history. Penance is over. The Web is not only cool again: It's hot. Sure, this time around it's different. The excitement, so vaporous in the bubble years, now pays dividends in hard coin. Productivity soars, costs plunge, and new markets come to life.

The companies in the Web Smart 50 saw it coming all along. They knew that smart info-tech investments would shake up the doughnut business and lift the next generation of stealth fighter jets skyward. During the downturn, they kept ponying up for Web technologies and methodically overhauling their businesses.

The Web Smart 50 profiles the most innovative projects within corporations. The trends that cut across industries are distilled into six categories, from collaboration and customer service to management. It makes for a diverse crew of companies, with plenty of surprises. Dell Inc. you would expect. But Whirlpool Corp. and the FBI? They offer innovations of their own. Add it all together, and it's a real-life portrait of the next stage of the Web. The Internet, it's clear, is being woven into every aspect of business and is shaking up entire industries. How so? Read on. —Heather Green
Patient Engagement Framework

Infor Me
Inform & Attract

Engage Me
Retain & Interact

Empower Me
Partner Efficiently

Partner With Me
Create Synergy & Extend Reach

Support My e-Community

National eHealth Collaborative
CIRCLE OF TRUST

YOU
<table>
<thead>
<tr>
<th>Purpose</th>
<th>Vocabulary &amp; Code Sets</th>
<th>Content Exchange / Utilization</th>
<th>Transport</th>
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<td>CVX</td>
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<td>HL7 2.5.1 + IG (inpatient only)</td>
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<td>SOAP RTM + XDR/XDM</td>
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</tbody>
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Patient Authored Documents Informative Document

Contents [hide]

1 Project Details
   1.1 Overview
   1.2 HL7 Project Scope
2 Subgroup Members
3 Meeting Logistics
   3.1 Meeting Schedule
   3.2 Meeting Agendas
   3.3 Meeting Minutes
4 Deliverable Timelines
5 Use Cases
6 Discussion on Header Attributes
7 Implementation Guide
8 Other Documents
9 Open Issues

Project Details

Overview
Announcements

- Please join us for the next Automate Blue Button All Hands Community Meeting, scheduled for Wednesday, August 29, 2012 at 3:00 pm Eastern. Meeting information is provided below.
- Missed the Kickoff? Download materials and watch the recording on the Meeting Artifacts page.
- If you are interested in joining the initiative, please sign up using the Join the Initiative page.
  - Once you have registered for ABBI, please sign up for a workgroup within the initiative.
Citizen and Patient Participation in Direct - Closing the Gap

Citizen and Patient Participation in Direct - Closing the Gaps
A DirectTrust White Paper Addressing How to Assure that Citizens, Patients, and Consumers Become Equal Participants in Direct Message Exchanges with Providers

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<tr>
<th>Document Version</th>
<th>Document Date</th>
<th>Revision Details</th>
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<tr>
<td>Version 1</td>
<td>August 1, 2012</td>
<td>Initial draft</td>
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<tr>
<td>Version 2</td>
<td>August 7, 2012</td>
<td>Minor revisions, wg consensus on direction and components written so far</td>
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<tr>
<td>Version 3</td>
<td>August 15, 2012</td>
<td>Sect. 1.3, first paragraph, new text. Section 3.0 added first draft</td>
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<tr>
<td>Version 4</td>
<td>August 20, 2012</td>
<td>Minor revisions, Section 4.0 added</td>
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Authors: DirectTrust Citizen and Patient Participation in Direct Workgroup members

1.0 Introduction

1.1 Overview of the Direct Project, the Value of Patient Participation in Directed Exchange, and the Potential for a "Trust Gap" to Develop

1.1.1 The purpose of this document is to describe the value of citizen and patient participation in Direct message exchange; to explicate the important roles played by trust agents in making Directed exchange operational at scale; and in particular the role of a Registration Authority in the process of identity verification; to highlight areas where barriers to a high level of citizen and patient participation may exist; and to suggest a number of alternatives and options to "close the gap" between citizen and consumer identity, and that of provider identity.
Health eDecisions Homepage

Announcements

- Join us for the next All Hands Work Group Meeting on **Thursday, August 23rd from 11:12:30 pm Eastern**. Meeting information is below.
- Plan on attending the HL7 Meeting in September? Please help us assess the Health eDecisions Community's participation by filling out a [quick questionnaire](#).
- Interested in becoming a Pilot Site for Health eDecisions? Fill out our survey form on the [RI/Pilots page](#).

Attend the Weekly Meetings

**Thursdays from 11:00-12:30 pm Eastern**

**Next Meeting:** Thursday, August 30, 2012 11:00 am, Eastern

**To Attend Meeting Go Here:** [https://siframework1.webex.com/siframework1/onstage/g.php?t=a&d=666664967](https://siframework1.webex.com/siframework1/onstage/g.php?t=a&d=666664967)

(Click link first, then dial in with Passcode and PIN provided by WebEx)

**Dial In:** **+1-408-600-3600**

**Access code:** 666 664 967
Transitions of Care (ToC) Initiative

Meeting Schedule

<table>
<thead>
<tr>
<th>Monthly All Hands Meeting</th>
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<tr>
<td><strong>Date of Next Meeting:</strong> August 6, 2012</td>
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<td><strong>Recurring Meeting:</strong> First Monday of Every Month from 4:00-5:00pm EDT</td>
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<td><strong>Webinar:</strong> <a href="https://siframek2.webex.com/siframek2/onstage/g.php?t=a&amp;d=662862199">https://siframek2.webex.com/siframek2/onstage/g.php?t=a&amp;d=662862199</a></td>
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<td><strong>Dial-in:</strong> 1-408-500-3600</td>
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NOTE: Meetings are now on the S&I Framework “Transitions of Care” Google Calendar. This calendar is colored taupe on the

Announcements

- If you are new to the Transitions of Care Initiative, start by reviewing the Transitions of Care Quickstart wiki page. The deliverables pertaining to the ToC Initiative in each phase of the S&I framework, from [background materials](#) to [implementation](#),

Charter
Product Infobutton

Product Brief - Context-Aware Knowledge Retrieval (Infobutton)

1 Product Brief - Context-Aware Knowledge Retrieval (Infobutton)
   1.1 Product Name - HL7 Version 3 Standard: Context-aware Information Retrieval (Infobutton), Release 1
      1.1.1 Topics
      1.1.2 Standard Category
      1.1.3 Integration Paradigm
      1.1.4 Type
      1.1.5 Releases
      1.1.6 Summary
      1.1.7 Description
      1.1.8 Business Case (Intended Use, Customers)
      1.1.9 Benefits
      1.1.10 Implementations/ Case Studies (Actual Users)
      1.1.11 Resources
         1.1.11.1 Work Groups
         1.1.11.2 Education
      1.1.12 Relationship to/ Dependencies on, other standards
      1.1.13 Links to current projects in development
   1.2 Product Name - HL7 V3 IG: URL-Based Implementations of the Context-Aware Information Retrieval (Infobutton)
      1.2.1 Type
      1.2.2 Releases
      1.2.3 Summary
Standards
LIBERATE
PATIENTS
HL7’s 26th Annual Plenary

Keynote Session 2: The Rise of e-Patients

9:15 – 9:50 am

*****

Lee Rainie

Director, Pew Research Center’s Internet & American Life Project;
Former Managing Editor, U.S. News & World Report
Lee Rainie is the Director of the Pew Research Center's Internet & American Life Project, a non-profit, non-partisan "fact tank" that studies the social impact of the internet.

The Project has issued more than 350 reports based on its surveys that examine people's online activities and the internet's role in their lives.

Lee is a co-author of the new book *Networked: The New Social Operating System*, a book about the social impact of technology that was written with Barry Wellman. He also is a co-author of *Up for Grabs, Hopes and Fears, Ubiquity, Mobility, Security*, and *Challenges and Opportunities* – a series of books about the future of the internet. Prior to launching the Pew Internet Project, Lee was managing editor of *U.S. News & World Report*. He is a graduate of Harvard University and has a master's degree in political science from Long Island University.
The Rise of e-Patients
How three tech revolutions have changed medicine

Lee Rainie, Director, Pew Internet Project
9.10.12
Health Level 7 International - Baltimore
Email: Lrainie@pewinternet.org
Twitter: @Lrainie
The story of e-patients (and netweavers)
Trudy and Peter Johnson-Lenz
New social operating system: Networked Individualism

• Social networks are more important
• Social networks are differently composed
• Social networks perform different functions
• Social networks are more vivid and tied to creation of information/media
Implications of networking individualism for health care

- Social networks (and the internet) provide “second opinions” – and can be sources of misinformation
- Providers are necessarily “nodes” in people’s social networks
- Social networks are allies and complements for care delivery
- Those in acute care use their networks differently from those with chronic conditions
- Providers are assessed and judged in more public ways
Digital Revolution 1: Broadband Internet (85%) and Broadband at home (66%)
Networked creators among internet users

- 69% are social networking site users
- 59% share photos and videos
- 37% contribute rankings and ratings
- 33% create content tags
- 30% share personal creations
- 26% post comments on sites and blogs
- 15% have personal website
- 15% are content remixers
- 16% use Twitter
- 14% are bloggers
- … of smartphone owners, 18% share their locations; 74% get location info and do location sharing
55% of adults own laptops – up from 30% in 2006

50% of adults own DVRs – up from 3% in 2002

45% of adults own MP3 players – up from 11% in 2005

42% of adults own game consoles

25% of adults own tablet computer – iPad, Kindle Fire

21% of adults own e-book readers - Kindle
Impact on health

• Empowered and engaged – 61% of all adults get health info online (80% of internet users)
• Participatory e-patients – 60% consume social media; 29% have contributed content
• Crowd-sourced via e-patients: 19% consult rankings/reviews of providers (5% post them); 18% consult reviews of hospitals (4% post them)
AMA press release
December 20, 2001
6. Remember that the Internet cannot replace a physician’s expertise and training .... If you have questions, trust your physician, not a chat room
Revolution 2: Mobile – 89% of adults

Mobile Subscriber Connections in America
ESTIMATED NUMBER OF MOBILE SUBSCRIBERS (MILLIONS)

Total U.S. population: 315.5 million

Source: CTIA
Changes in smartphone ownership

- Smartphone: 35% (May 2011) to 46% (February 2012)
- Other cell phone: 48% (May 2011) to 41% (February 2012)
- No cell phone: 17% (May 2011) to 12% (February 2012)
The rise of apps culture - 50% of adults

- Download apps to their phone: 22%, 29%, 38%
- Have preloaded apps on their phone: 38%, 43%
- Total who have apps on phone: 43%, 50%

Pew Internet & American Life Project
Mobile health apps

All (n=658) 29%
Urban (n=203) 33%*
Suburban (n=322) 29%*
Rural (n=100) 20%
18-29 (n=224) 28%*
30-49 (n=276) 32%*
50+ (n=145) 20%
Impact on health

• Real-time – 35+% use mobile phone for health info; 29% have health apps on handhelds

• Place-less and time-less

• Over-represented among young, minorities, urban residents, upper SES

• **NO FEMALE/MALE DIFFERENCES**
Digital Revolution 3

Social networking – 52% of all adults

% of internet users

- 18-29
- 30-49
- 50-64
- 65+

2005 2006 2007 2008 2009 2010 2011 2012

Pew Internet
Pew Internet & American Life Project
Impact on health

• “Last search”: 48% for others; 36% for self; 11% for both

• Read others’ commentaries: 34%

• Find others who have same condition: 18%

• Get info from social networking site: 11% SNS users

• Get info from Twitter: 8% of Twitter users
How people make medical decisions

• Mindset – general approach to medicine
• Data/Numbers – and how they are presented
• Stories
How online searches affect decisions (1)

• 60% of e-patients say the information found online affected a decision about how to treat an illness or condition.
• 56% say it changed their overall approach to maintaining their health or the health of someone they help take care of.
• 53% say it lead them to ask a doctor new questions, or to get a second opinion from another doctor.
How online searches affect decisions (2)

• 49% say it changed the way they think about diet, exercise, or stress management.
• 38% say it affected a decision about whether to see a doctor.
• 38% say it changed the way they cope with a chronic condition or manage pain.
The networked world of e-patients

<table>
<thead>
<tr>
<th>What providers are good for</th>
<th>What others are good for</th>
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<tbody>
<tr>
<td>• Diagnosis / treatments</td>
<td>• Emotional support</td>
</tr>
<tr>
<td>• Prescriptions</td>
<td>• Practical advice for day-to-day coping</td>
</tr>
<tr>
<td>• Recommendation for specialist</td>
<td>• Recommendation for quick remedy for everyday issue</td>
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<tr>
<td>• Recommendation for hospital</td>
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<tr>
<td>• Info on alternative treatments</td>
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What’s a doctor to do about e-patients?

• Minimum engagement
  – “Tell me what you’re thinking” - Groopman
  – Ask about patients’ internet use, exposure on social networking, what they post and read

• Medium engagement
  – Ask if patients would be willing to be let you/staff be a node on social media

• Heavy engagement
  – Do it yourself
What social networks do for patients: Why physicians can be “nodes”

- **Attention** – *act as sentries*
  - alerts, social media interventions, pathways through new influencers
- **Assessment** – *act as trusted, wise companion*
  - help assess the accuracy of info, timeliness of info, transparency and rigor of info
- **Action** – *act as helpful producers/enablers*
  - help give people outlets for expression, interpretation of their creations
Health outcomes payoff

- Monitoring
- Interventions and reinforcement
- Skills training – meds/devices
- Emotional and social support among peers
- “Information prescriptions”
- Amateur research contributions – online recruitment, communities and clinical trials
Be not afraid
Thank you!
HL7’s 26th Annual Plenary

Keynote Session 3: The Consumer Empowerment

9:50 – 10:25 am

*****

Elaine Blechman, PhD

Professor Emerita, University of Colorado-Boulder;
President, Prosocial Applications
Elaine A. Blechman, PhD, is founder and president of Prosocial Applications and Professor Emerita of Psychology, U. of Colorado. Dr. Blechman's early research on behavioral medicine, supported by the National Institute of Mental Health and the National Institute of Drug Abuse, resulted in seven books and over ninety peer-reviewed journal articles and book chapters. Her more recent interest in the role of health information technology in patient and provider behavior led to her service as first co-chair of the consumer empowerment technical committee, ANSI/HIMSS Health Information Technology Standards Panel and board member of the Public Health Data Standards Consortium. Dr. Blechman created Prosocial's family of cloud-hosted, patient-centered SmartPlatforms™, including SmartPHR®, SmartEHR®, SmartHIE®, and SmartHIX™ and led Prosocial through product development and usability testing phases. Parelleling introduction of SmartPlatforms™ into the marketplace, Dr. Blechman advises early adopters about how they can use patient-centered health IT to achieve Donald Berwick's "triple aim": improved experience of care, improved population health, and reduced per capita costs of health care.
The Consumer Empowerment Paradox

Elaine A. Blechman, PhD
Peter Raich, MD
HL7 Plenary Keynote
September 10, 2012
Health Care Homogeneity

• Atul Gawande, MD “Medicine has long resisted the productivity revolutions that transformed other industries. But the new [hospital] chains aim to change this.”

• Jacob Appel, MD “As both a practicing physician and a patient, I do not want my medicine prepared and served one-size-feeds-all, like a beet salad with goat cheese.”
The Consumer Empowerment Paradox

The belief that homogeneous health IT standards can empower heterogeneous patients.

Arjit Guha using Twitter got his health insurance carrier to pay for his cancer treatments.
Heterogeneous Cancer Survivors

- 12 million cancer survivors in 2012
- 18 million cancer survivors by 2022
- 7 million over 65
- 54% women
- 22% with breast cancer
- 19% with prostate cancer
- 10% with colorectal cancer
- 4.7 million diagnosed more than 10 years ago
Actionable Knowledge

All Electronically Available Health Information

Patient-Specific Data

Evidence-Based Data

Actionable Knowledge
Actionable Knowledge is **patient-specific** and **evidence-based**.

- **Patient-Specific**
  - gender
  - age
  - zip code
  - social support
  - family history
  - safety errors
  - health insurance

- **Evidence-Based**
  - tumor size
  - DNA profile
  - hormone marker
  - tumor site
  - chronic conditions

*References*
"We couldn’t sit back and let this woman have her healthy breasts cut off"
Decisions cancer survivors make require actionable knowledge.

**Patient-Specific Data**
- age
- gender
- zip code
- social support
- family history
- tumor size
- diagnosis
- hormone marker
- DNA profile
- chronic conditions
- safety errors
- health insurance

**Evidence-Based Data**
A 45 year old single mother with teenage children is diagnosed with early stage breast cancer. She has no health insurance and must quickly return to work to support her family. Her surgeon discusses initial treatment choices of mastectomy (removing the entire breast) vs. lumpectomy (breast sparing), explaining that for the two treatments to be equally effective in preventing recurrence, the lumpectomy surgery has to be followed-up with 6 weeks of daily radiation. She chooses the single procedure mastectomy for economic and time reasons.
A 73 year old physically active man is diagnosed with early stage prostate cancer. His physician discusses treatment options including surgery, radiation therapy and surveillance without treatment at this time. Surgery and radiation are associated with a 25% chance for incontinence and impotence. The majority of men his age will die of causes other than prostate cancer. After weighing the pros and cons, the patient chooses close surveillance, deferring specific treatment, since he values his current quality of life.
A 30-year old man is diagnosed with colon cancer that has spread from the large bowel to the adjacent lymph nodes. The surgeon explains to the patient and his wife that the chance of the cancer coming back after surgery is 60%, with recurrence risk reduced to 30% by the addition of chemotherapy every 2 weeks for 6 months. After discussion of risk reduction, side effects and possible complications the patient and his wife choose surgery plus chemotherapy.
A 65 year old woman is diagnosed with breast cancer that has spread to the lymph nodes in the arm pit (axilla). Her cancer characteristics include: intermediate grade, hormone-receptor positive and HER-2 negative. Standard treatment for lymph node positive breast cancer includes surgery, followed by chemotherapy and hormone therapy. Her oncologist describes a test that identifies women in her age group who do not need chemotherapy, which will cost her $4,000, with only $80 covered by her insurance. The patient chooses the test, which she can afford, rather than endure 4-6 months of possibly needless chemotherapy.
Sources of Patient Heterogeneity
(a) Amount of Actionable Knowledge
(b) Accessibility of Actionable Knowledge
(c) Frequency of Independent Payers and Providers
HIT Standards Now Work for
Relatively healthy patients receiving all care and insurance from (a) a few providers and payers who have accumulated a small amount of actionable knowledge, (b) most of which is accessible to patients.
Accumulation of actionable knowledge in GB

Patient’s Lifetime Number of Independent Payers and Providers of Health Care Services

Health IT Standards Must Also Work for Chronically ill patients with many providers and payers who have (a) accumulated much actionable knowledge, (b) of which little is accessible to patients.
Top-Down HIT Standards Model: Empower All Consumers Via Provider-Driven Partnerships

1. Health IT Standards
2. Actionable Knowledge (AK)
3. Provider Use of AK
4. Patient Use of AK
5. Provider-Patient Review of AK
6. Shared Decision Making
7. Trust Disclosure Satisfaction Optimism
8. Patient Adherence to Care Plan
9. Patient Health Outcomes

Empower all consumers via provider-driven partnerships.
Meaningful Use Stage 2 objectives

1. Improve quality, safety, efficiency, and reduce health disparities
2. Engage patients and families in their health care
3. Improve care coordination
4. Improve population and public health
5. Ensure adequate privacy and security protections for personal health information

endorse consumer empowerment.
Standards for MU 2 data set

<table>
<thead>
<tr>
<th>Table 2. Common MU Data Set</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patient name</td>
</tr>
<tr>
<td>2. Sex</td>
</tr>
<tr>
<td>3. Date of birth</td>
</tr>
<tr>
<td>4. Race</td>
</tr>
<tr>
<td>5. Ethnicity</td>
</tr>
<tr>
<td>6. Preferred language</td>
</tr>
<tr>
<td>7. Smoking status</td>
</tr>
<tr>
<td>8. Problems</td>
</tr>
<tr>
<td>9. Medications</td>
</tr>
<tr>
<td>10. Medication allergies</td>
</tr>
<tr>
<td>11. Laboratory test(s)</td>
</tr>
<tr>
<td>12. Laboratory value(s)/result(s)</td>
</tr>
<tr>
<td>13. Vital signs (height, weight, BP, BMI)</td>
</tr>
<tr>
<td>14. Care plan field(s), including goals and instructions</td>
</tr>
<tr>
<td>15. Procedures</td>
</tr>
<tr>
<td>16. Care team members</td>
</tr>
</tbody>
</table>

can capture patient-specific data.
Standards for EHR certification

- CPOE
- Drug-Drug Interaction
- Demographics
- Vital Signs, Body Mass, Growth Chart
- Problem List
- Med List
- Med-Allergy List
- Clinical Decision Support
- Drug-Formulary Checks
- Smoking Status
- Patient-List Creation
- Patient-Specific Ed Resources
- Advance Directives
- Transitions of Care
- Electronic Prescribing
- Incorporate lab tests and results
- Authentication, Access Control, Authoriza’n
- Auditable Events, Tampering, Audit Reports
- Automatic Log-Off
- Emergency Access
- End-User Device Encryption
- Integrity
- Accounting of Disclosures
- View, Download, Transmit to 3d Party
- Clinical Summaries
- Immunization Info, Transmit to Registry
- Transmit Public-Health Info to Registry
- Transmit Reportable Lab Tests
- Automated Measure Calculation

can link patient-specific to evidence-based data
### Standards for base EHR certification

**Table 6. Certification Criteria Required to Satisfy the Base EHR Definition**

<table>
<thead>
<tr>
<th>EHR technology that:</th>
<th>Certification Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Includes patient demographic and clinical health information, such as medical history and problem lists</td>
<td>Demographics § 170.314(a)(3)</td>
</tr>
<tr>
<td></td>
<td>Problem List § 170.314(a)(5)</td>
</tr>
<tr>
<td></td>
<td>Medication List § 170.314(a)(6)</td>
</tr>
<tr>
<td></td>
<td>Medication Allergy List § 170.314(a)(7)</td>
</tr>
<tr>
<td>Has the capacity to provide clinical decision support</td>
<td>Clinical Decision Support § 170.314(a)(8)</td>
</tr>
<tr>
<td>Has the capacity to support physician order entry</td>
<td>Computerized Provider Order Entry § 170.314(a)(1)</td>
</tr>
<tr>
<td>Has the capacity to capture and query information relevant to health care quality</td>
<td>Clinical Quality Measures § 170.314(c)(1) through (3)</td>
</tr>
<tr>
<td>Has the capacity to exchange electronic health information with, and integrate such information from other sources</td>
<td>Transitions of Care § 170.314(b)(1) and (2)</td>
</tr>
<tr>
<td></td>
<td>Data Portability § 170.314(b)(7)</td>
</tr>
<tr>
<td>Has the capacity to protect the confidentiality, integrity, and availability of health information stored and exchanged</td>
<td>Privacy and Security § 170.314(d)(1) through (8)</td>
</tr>
</tbody>
</table>

can aggregate actionable knowledge.
**Final Rule HIT standards**

<table>
<thead>
<tr>
<th>Standard Type</th>
<th>Specification Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>§170.202 Transport</td>
<td>XDR, XDM Direct Messaging</td>
</tr>
<tr>
<td>§170.204 Functional</td>
<td>Web Content Accessibility Guidelines (WCAG) 2.0</td>
</tr>
<tr>
<td>§170.205 Content Exchange</td>
<td>HL7 Implementation Guide for CDA® Release 2: IHE Health Story Consolidation</td>
</tr>
<tr>
<td>§170.207 Vocab Standards</td>
<td>CDA Implementation Guide for Cancer Reporting</td>
</tr>
<tr>
<td></td>
<td>SNOMED CT®</td>
</tr>
</tbody>
</table>

Can make actionable knowledge accessible to chronically ill patients.
But, MU2 criteria are minimal.

<table>
<thead>
<tr>
<th>MU Stage 2 Standards-Based Objectives</th>
<th>MU Stage 2 Requirements for Eligible Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CORE</strong></td>
<td></td>
</tr>
<tr>
<td>1 CPOE</td>
<td>60% of medication, 30% of laboratory, 30% of radiology order</td>
</tr>
<tr>
<td>2 eRX</td>
<td>&gt;50% all permissible prescriptions</td>
</tr>
<tr>
<td>3 Demographics</td>
<td>&gt;80% of all unique patients</td>
</tr>
<tr>
<td>4 Smoking Status</td>
<td>&gt;80% of all unique patients, age 13+</td>
</tr>
<tr>
<td>5 Clinical Decision Support (CDS)</td>
<td>5 CDS interventions related to 4+ clinical quality measures</td>
</tr>
<tr>
<td>6 Incorporate clinical lab test results</td>
<td>&gt;55% all clinical lab test results ordered with binary or numerical results</td>
</tr>
<tr>
<td>7 Patient Lists</td>
<td>1 report listing patients with a specific condition</td>
</tr>
<tr>
<td>8 Patient Reminders</td>
<td>1 reminder to &gt;10% of all unique patients with 2+ office visits in 24 mos</td>
</tr>
<tr>
<td>9 Patients can view online, download, transmit health information</td>
<td>(1) &gt;50% of all unique patients provided online access within 4 business days to their health information &quot;subject to the EP’s discretion to withhold certain information&quot; (2) &gt;5% of all unique patients view, download, or transmit to 3rd party health information.</td>
</tr>
<tr>
<td>10 Clinical Summaries</td>
<td>Within 1 business day for &gt;50% of office visits</td>
</tr>
<tr>
<td>11 Patient-Specific Education Resources</td>
<td>&gt;10% of all unique patients</td>
</tr>
<tr>
<td>12 Secure Electronic Messaging</td>
<td>1 secure message sent by &gt;5% of all unique patients</td>
</tr>
<tr>
<td>13 Medication Reconciliation</td>
<td>Performs 1 med rec for &gt;50% of patients admitted to EP’s practice.</td>
</tr>
<tr>
<td>14 Summary of Care Record</td>
<td>(1) EP provides Summary for &gt;50% of referrals; (2) EP provides Summary electronically for &gt;10% of referrals either (a) electronically transmitted from CEHRT to recipient or (b) exchangedr consistent with ONC mechanism for Nationwide Health Information Network (NwHIN)</td>
</tr>
<tr>
<td>15 Electronic Submission of Immunization Data</td>
<td>Successful ongoing submission to immunization registry in accordance with applicable law and practice.</td>
</tr>
<tr>
<td>16 Electronic Submission of Lab Results</td>
<td>Successful ongoing submission to public health agencies in accordance with applicable law and practice.</td>
</tr>
<tr>
<td>17 Electronic Submission of Syndromic Surveillance Data</td>
<td>Successful ongoing submission to public health agencies in accordance with applicable law and practice.</td>
</tr>
<tr>
<td>18 Protect Electronic Health Information</td>
<td>Conduct or review security risk analysis per 45 CFR 164.308(a)(1), including addressing encryption/security of data stored in CEHRT per 45 CFR 164.312(a)(2)(iv) and 45 CFR 164.306(d)(3) and implement security updates as necessary and correct identified security deficiencies.</td>
</tr>
</tbody>
</table>
Minimal MU2 criteria limit cancer survivor access to actionable knowledge.

<table>
<thead>
<tr>
<th>MU Stage 2 Standards-Based Objectives</th>
<th>MU Stage 2 Requirements for Eligible Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Advance Directive Indicated as Structured Data</td>
<td>No option for E.P.s (hospital &gt;50% patients 65yrs +)</td>
</tr>
<tr>
<td>2 Imaging Results (Image &amp; Explanation) Accessible Electronically</td>
<td>&gt;10% of all tests ordered by EP accessible via CEHRT</td>
</tr>
<tr>
<td>3 Record family health history structured data</td>
<td>&gt;20% of all unique patients</td>
</tr>
<tr>
<td>4 Record electronic notes in patient records</td>
<td>1 electronic progress note for &gt;30% of unique patients with office visits</td>
</tr>
<tr>
<td>5 Capability to identify and report cancer cases</td>
<td>Successful ongoing submission of cancer case information from CEHRT to public health central cancer registry in accordance with applicable law and practice.</td>
</tr>
<tr>
<td>6 Capability to identify and report specific cases</td>
<td>Successful ongoing submission of specific cases from CEHRT to specialized registry in accordance with applicable law and practice.</td>
</tr>
</tbody>
</table>
MU2 requirements cannot significantly increase accessibility of actionable knowledge for cancer survivors above pre-MU1 levels.
Health IT Standards

Actionable Knowledge (AK)

1. Actionable Knowledge (AK)

2. Patient Use of AK

3. Provider Use of AK

4. Patient-Provider Review of AK

5. Shared Decision Making

6. Trust Disclosure Satisfaction Optimism

7. Patient & Provider Care Plan Adherence

8. Patient Health Outcomes

9. Actionable Knowledge (AK)

Bottom-Up HIT Standards Model: Empower Cancer Survivors Via Consumer-Driven Partnerships
Invert the TOC Initiative and Consolidated CDA

U.S. Health and Human Services
Office of the National Coordinator for Health IT

S&I Framework

Standards & Interoperability Framework

Transitions of Care Initiative
Companion Guide to HL7 Consolidated CDA
for Meaningful Use Stage 2

to create bottom-up standards.
Using Health Story incrementalism get the data flowing to cancer survivors and clinicians.
1. Clinical Summary Scenario

a. After each provider visit or hospital discharge
b. A patient-driven PHR
c. Requests and receives
d. MU2 Summary of Care data elements
e. Via CCDA from provider or hospital EHRs for:
f. Reconciliation with current clinical summary data
g. Patient access to comprehensive clinical data
h. Return of updated CCDA with queries
i. Receipt of responses to queries
2. Health Care Spending Scenario

a. After each provider visit or hospital discharge
b. A patient-driven PHR requests and receives
c. Via CCDA from provider, hospital, payer systems
d. Invoices submitted to patients and insurers,
e. Insurer notifications of claims paid and denied,
f. Clinical documentation, and
g. Correspondence about dispute resolution for:
h. Reconciliation with current financial data
i. Patient management of health care spending
j. Return of updated CCDA with queries
k. Receipt of responses to queries
3. Care Plan Scenario

a. After each provider visit or hospital discharge
b. A patient-driven PHR requests and receives
c. Consults, instructions, orders, recommendations, referrals, selected decision supports and quality measures, treatment plans
d. Via CCDA from provider or hospital EHRs for:
e. Reconciliation with current care plan data
f. Patient-provider shared decision making
g. Return of updated CCDA with queries
h. Receipt of responses to queries
4. Query Scenario

A patient-driven PHR, after attempting to reconcile incoming CCDA data with current data, returns an updated CCDA with queries about:

a. Safety: Auto-calculation finds dangerous levels of radiation from repeat MRIs.

b. Accuracy: Patient noted missing and incorrect drug allergies.

c. Efficiency: Two providers ordered the same lab tests in the same month.

d. Quality: No treatments have been recommended based on patient-specific quality measures.

e. Coordination gaps: There has been no primary-care follow-up on specialist recommendations.
Nothing empowers consumers like actionable knowledge.
26th ANNUAL PLENARY—PANEL SESSION:

Presentations from different stakeholders in the mobile health space on how they view the future of mobile health and HL7’s potential role in this evolving arena

10:50 am – 12:20 pm

*****

Moderator

Doug Fridsma, MD, PhD
Director, Office of Standards and Interoperability, Office of the National Coordinator for Health IT

Panelists

Charles (Chuck) Parker
Executive Director, Continua Health Alliance

Christoph Lehmann, MD
Professor of Pediatrics and Biomedical Informatics, Vanderbilt University

Jim St. Clair
Senior Director, Interoperability and Standards, HIMSS

Lonnie Smith
Policy Analyst, U.S. Food and Drug Administration (FDA)

Heather Llewelyn Grain
Standards Australia
Panel Session: Presentations from different stakeholders in the mobile health space on how they view the future of mobile health and HL7’s potential role in this evolving arena

Charles (Chuck) Parker
Executive Director, Continua Health Alliance

Charles (Chuck) Parker is the executive director of the Continua Health Alliance – a membership-driven company focused on developing an eco-system of interoperable personal health devices. Through working with standards bodies and industry experts, Continua publishes certification standards built upon international criteria from IEEE, HL7, Bluetooth, USB, and others. Chuck leads the many workgroups and day-to-day operations of the Alliance.

Mr. Parker has over 20 years of experience in healthcare technology, policy, and the strategic design of evaluation and measurement strategies. He has led national programs for practice transformation and has served on national committees for assessing adoption requirements.

Mr. Parker holds a Master of Science degree in Healthcare Informatics from Northeastern University. He earned his BA in Communication Studies and Business Management at Texas Tech University in Lubbock.
Dr. Lehmann first became interested in the medical applications of information technology in the mid-1990s, when he developed the first web-based interactive patient simulation with a natural language interface at Marshall University. Since then, he has designed, developed, implemented, and evaluated several computer-based applications, used at Hopkins Children’s and elsewhere, including:

- A computerized order tool to reduce medication errors in children undergoing cancer treatment
- An online infusion calculator to reduce medication errors in children undergoing IV infusions integrated into the POE system
- A system that monitors lab values of critically ill preemies and alerts physicians when their scores become abnormal
- A web-based program to approve special categories of restricted antibiotics as a faster and safer alternative to phone or fax orders
- A PICU bed occupation forecasting module that allows better management of bed resources.
- A novel interface for physiologic monitor data that allows providers to recognize certain medical conditions faster.

In 2009, Dr. Lehmann conceived and launched the journal *Applied Medical Informatics*, devoted to original research and commentary on the use of computer automation in the day-to-day practice of medicine. ACI (www.aci-journal.org) is published by Schattauer Verlag, Stuttgart, Germany, and Dr. Lehmann served as the Editor-in-Chief since its inception. In 2009, he co-authored and published *Pediatric Informatics*, the first textbook on this subject. He is also the co-founder and chief information officer of *Dermatlas*, an open-access international web database for pediatricians and dermatologists.

Dr. Lehmann has served on the board of the American Medical Informatics Association since 2008 and currently serves as the organization’s secretary. In 2010, he was inducted as a fellow into the American College of Medical Informatics and in 2012, he will become one of the Vice Presidents of the International Medical Informatics Association.

In 2010, Dr. Lehman was appointed Medical Director of the Child Health Informatics Center for the American Academy of Pediatrics and joined the National Quality Forum’s newly formed advisory committee on health information technology.

Over the years, he has directed several classes and courses in Clinical Informatics, including an ONC funded program. Dr. Lehmann was appointed to the commission that is writing the first board exam for the new specialty of Clinical Informatics. He is a speaker at national and international meetings and has served on many scientific program committees. He is slated to be the Editorial Chair for the 2013 MedInfo conference in Copenhagen, Denmark.

Dr. Lehmann’s current academic appointments include Professor of Pediatrics and Biomedical Informatics at Vanderbilt University.
For a summary of Dr. Lehmann’s publication record, please visit Google Scholar at http://scholar.google.com/citations?user=ASxrCMwAAAAJ

Jim St. Clair is a Senior Director for Interoperability and Standards for HIMSS, the largest U.S. cause-based, not-for-profit healthcare association focused on the optimal use of information technology and management systems for the betterment of healthcare.

St. Clair joined HIMSS in 2011. In his current role, he oversees, standards, interoperability, and privacy and sustainment of Integrating the Healthcare Enterprise (IHE) initiatives in the US and internationally.

Previously, St. Clair was Director of Government and Healthcare Solutions at AGJ Systems and Networks, a disabled veteran-owned small business providing IT governance, architecture, project management and managed services, in partnership with superior technology partners. He provided support to numerous government and healthcare customers in implementing technology solutions, assessing security, risk and managing regulatory compliance.

Additionally, St. Clair has been active in numerous associations, including the Association of Government Accountants (AGA); Global Association of Risk Professionals (GARP); and the National Association of State CIOs (NASCIO). He also chaired a HIMSS Working Group in Medical Banking. He has served on the Federal Working Group in XBRL-US and has developed several white papers and presentations in the Extensible Business Reporting Language (XBRL).

St. Clair also completed 10 years in the US Navy, serving in various capacities along the East Coast and Washington, DC. During this time, he served in several federal working groups in technology and national security.

A prolific speaker and presenter, St. Clair is a Certified Information Security Manager (CISM), a Six Sigma Green Belt (SSGB) with the American Society for Quality (ASQ), and a Project Management Professional (PMP). He earned a BA in Business Administration from the University of Mississippi.
Lonnie Smith
Policy Analyst, U.S. Food and Drug Administration (FDA)

Lonnie Smith, Policy Analyst, has been a member of the Food and Drug Administration’s Data Standards Council (DSC) since 2003. As a member of the FDA DSC's Structured Product Labeling (SPL) team, he has collaborated with several FDA medical product centers to adopt and implement SPL as a health and regulatory data standard.

Heather Llewelyn Grain
Standards Australia

Heather has international, national, state and local experience in health consumer representation and health informatics in both traditional and technology areas. She has represented Consumers Australia in eHealth standards for more than 10 years as a technical expert consumer.

Her standards involvement is also long standing, including participation and development of eHealth standards through Standards Australia – Health Informatics Committee (IT14) (which she has chaired), ISOTC215 Convenor semantic content working group and as a co-chair in HL7.
Child Health Informatics and the American Academy of Pediatrics: Empowering Children and Families

Health Level Seven® International
September 2012 Annual Plenary and Working Group Meeting

Christoph U Lehmann, MD, FAAP, FACMI
Objectives

- Share the AAP’s Infrastructure for HIT
- Provide an overview to the AAP’s HIT activities and initiatives
- Discuss important AAP pediatric HIT activity
  - Discuss the Pediatric Model EHR
- Future Vision
  - Web service Model
AAP Overview

- Founded in 1930, the American Academy of Pediatrics (AAP) and its member pediatricians dedicate their efforts and resources to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults.

- The AAP has approximately 60,000 members in the United States, Canada, Mexico, and many other countries.
The Value Proposition of the AAP

- **Children’s Health Expertise** – The AAP is the premier membership organization of the pediatric profession and is the widely recognized standard bearer for pediatric health care. For example, pediatricians provide 84% of all well visits and 76% of all sick visits to infants and children under age 6.

- **Premier Pediatric Publisher** - The AAP is the publisher of the pediatric evidence-based guidelines that drive pediatric clinical care. AAP content comes from the nation's leading child health experts and is supported by scientific research. The content is backed by the AAP, its members, and expert committees, councils and sections.
Approximately 25% of pediatricians report using an EHR system, compared to 43% of adult providers.

- Systems often designed for adult care
- Systems are expensive
- Systems lack the functionality necessary to support pediatric care
- Pediatric health system is not optimizing long-term health and financial returns on investments HIT
Pediatrics is Special

- Children have different needs
  - Immunization management
  - Weight-based dosing
- Guardianship considerations
- Variability in care location & setting
- Specific pediatric functionality
  - Age
  - Identification
  - Growth
  - Privacy
Authorised by AAP Board in October 2009

Founded in May 2010

Serves as the AAP “home” for HIT initiatives

Directed by Christoph U. Lehmann, MD, FAAP, FACMI (founding Medical Director)

Governed by an 7-person Project Advisory Committee
Child Health Informatics

To meet the need for supporting Health Information Technology (HIT), the AAP launched the Child Health Informatics Center (CHIC). The center has focused its efforts on positioning itself as the “home” for HIT initiatives and demonstrates the Academy’s commitment to ensuring that pediatrics is considered in national discussions about HIT, that members are provided with timely information and guidance during this time of rapid change, and most importantly, that children have access to high quality care.

Center Objectives

- Build awareness about the importance of HIT as it relates to improved quality and efficiency of pediatric care
Electronic Health Record Evaluation Site

- Offers the ability to research various EMR products with pediatrician reviews
- Currently the site hosts 150 reviews on 31 different products
- Buddy List feature = links pediatricians with peers to assist with EHR implementation

www.aapcocit.org/emr/
Immunization Information Systems (IIS) Toolkit

- IIS are known as Immunization Registries
- Legal statutes/regulation and funding usually at the state level.
- Standards are available for exchanging data between IIS and EHRs; not all IIS use the standards
- IIS Toolkit is for AAP chapters and other local advocates with a resource for discussions with IIS administrators and public health agencies
- CHIC Resource Library
Toolkit Topics and Links

- **ARRA | Meaningful Use**
  - *CHIC Website: Meaningful Use Overview* - [www.aap.org/informatics/AAPOverview.html](http://www.aap.org/informatics/AAPOverview.html)

- **Standards**
  - *HIT Standards Committee* - [http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__health_it_standards_committee/1271](http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__health_it_standards_committee/1271)

- **Health Information Exchanges (HIE) and Regional Extension Centers (REC)**
  - *CHIC Website: State Pages* - [www.aap.org/informatics/StateResource.html](http://www.aap.org/informatics/StateResource.html)

- **Continued Education**
  - *COCIT Educational Programs* - [www.aap.org/informatics/COCITEducationalPrograms.html](http://www.aap.org/informatics/COCITEducationalPrograms.html)
HIT Chapter Educational Program

- REC Engagement to:
  - Provide pediatric specific education
  - Connect member practices with REC resources

- CHIC’s Regional Extension Center Workgroup
  - Chapter Educational funds from AAP
  - 4 chapters with $4000 each to engage RECs
  - Local Conferences
    - 1) Help member practices adopt/implement an EHR and
    - 2) Provide strategies as to how members can access REC service
Development of a Model EHR Format

- Grant from the Agency for Healthcare Research and Quality

- Development of a Model EHR Format
  - $4.7M – 2 year project (Limited eligible bidders)
  - AAP Subcontract from Westat
    - Technical Expert Panel
    - Provided content expertise for environmental scan
    - In-depth Interviews
    - Development and review of model EHR format requirements
    - Dissemination of Model EHR Format
What is a “Format?”

Called for in the Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA)

Further defined as requirements for:

- Minimum set of data elements
- Applicable data standards
- Usability
- Functionality
- Interoperability
Existing EHR systems often do not optimally support the provision of health care to children

Project components

- Identify gaps between existing systems and an optimal EHR for children
- Design, develop, test, and disseminate a Format based on those gaps
- Assess existing products for conformance with the Format
- Demonstrate use of the Format in prototype development
Scope of Work

Focus

- Requirements for the unique *incremental* needs of Children
- Build on existing foundational work
- Suitable for existing and potential systems
- Primary care and general inpatient needs

Constraints

- Schedule for Format development
- Not a standards-setting process
Prior Work

- HL7 EHR-S Functional Model
  - Hierarchy
  - Not child-specific
- HL7 Child Health Functional Profile
  - 125-150 child-specific changes from Functional Model
- Numerous publications
- Selected home-grown systems
Topic Areas in Format

- Activity Clearance
- Birth History
- Child Abuse Reporting
- Child Welfare
- Children with Special Health Care Needs
- Growth Data
- Immunizations
- Medication Management
- Newborn Screening
- Parents, Guardians, and Family Relationship Data
- Patient Identifiers
- Patient Portals/Personal Health Record Information Access
- Prenatal Screening
- Primary Care
- Quality Measures
- Registry Linkages
- School-based Linkages
- Security and Confidentiality
- Special Terminology and Information
- Specialized Scales and Scoring
- Well Child and Preventive Care
Requirements Development Process

For each topic area:

- Review findings from gap analysis
- Initial requirements drafted by subject matter expert (SME)
- Project team review
- Outside SME and TEP review(s)
From the HL7 Child Health Functional Profile:

- “The system **MAY** provide the ability to compute post conceptional age (corrected age) for the purposes of decision support.”
From the Model Format:

“The system SHOULD be able to display head circumference adjusted for the degree of prematurity by subtracting the number of weeks premature the individual was born from each plot point during the first two years of life. The growth chart should reflect that this plot was corrected for prematurity.”
Format Characteristics

- Specialized requirements database (Accompa)
- Chiefly functional requirements, including interoperability
- Usability challenges
- Few existing standards to support taxonomy or data elements
- >700 detailed requirements
- Suitable for system development and system selection
Electronic Translation of Academy Clinical Content
Electronic Translation of Academy Clinical Content (eTACC) Initiative

- Develop a mechanism and process to translate key Academy clinical content into formats suitable for use within electronic systems
  - Review of content and extraction of actionable guidelines (e.g., assessment, screening, referrals, counseling, etc)
  - Ranking of critical clinical and psychosocial areas traditionally addressed in an office visit for format development
  - Translation and development of toolkit
  - Prioritizing of actionable items
  - Testing and integration feasibility
**Vision:** policy / guidelines are “information substrate” which systems should be developed from

- To improve the ability of pediatricians to implement AAP recommendations at the point of care
- To ensure that EHR vendors can incorporate these guidelines into electronic decision support systems

**Current Focus:** document clarity / specificity in both guidance & information content

**Future focus:** development of information “building blocks” used in HIT, HIE, quality measurement, research
Promoting Child Development

INTRODUCTION
Any health supervision encounter with children involves promoting healthy child development. Understanding child development and the application of its principles sets the care of children apart from that of adults. Infants must grow to be children, then adolescents, and then adults. Health promotion to ensure physical, cognitive, and social emotional health as well as to protect the child from infectious diseases and injuries (intentional and unintentional) supports the healthy development of the child. Successful health promotion efforts should take into account the developmental reality of the child now, as well as her developmental expectations for the next months and her developmental potential for growth over time.

Encouraging development of the growing child recognizes the wonder of 'brain development with its concurrent increases in volume, size, and synapse formation. Physical growth to support brain development is essential. Even more important are the influences of stimulation, social interaction, family, culture, and community. The development of the infant, child, youth with special health care needs is addressed in separate sections within this theme. Even a child whose brain growth and function have been impaired by injury or early neglect has a developmental potential that must be discovered and supported to achieve the best possible outcome for that child.'

Monitoring Child and Adolescent Development
Developmental surveillance and screening of children and adolescents are integral components of health care supervision. Surveillance of children and adolescents is a continuous and cumulative process that is used to ensure optimal health outcomes. For example, it is essential in identifying and tracking children with developmental and behavioral problems. Early detection of children with developmental delays is critical in diagnosing and providing early therapeutic interventions. The parents' report of current skills can accurately identify developmental delays, even though they may not.

BOX 2
Promoting Literacy
To help parents promote healthy language and cognitive development in young children, Bright Futures recommends anticipatory guidance on reading aloud at every health supervision visit from 6 months to 5 years and encourages giving a book at these visits, whenever possible, especially for children at socioeconomic risk.

Many organizations make books available at a low or no cost for distribution. For example, Reach Out and Read (http://www.readoutandread.org) is a national nonprofit organization that promotes early literacy by making books a routine part of pediatric primary care so that children grow up with books and a love of reading. Information on railings, technical assistance, and startup funding for these books is available for practices or clinics that are interested in implementing a Reach Out and Read program.

SOCIAL-EMOTIONAL SKILLS
As parents learn to recognize their infant's behavior cues for engagement and disengagement or distress, and consistently respond appropriately to their infant's needs (e.g., being fed when hungry or comforted when crying), babies learn to trust and love their parents.

Reading aloud is an important way to encourage language development (Box 2).

Separation Anxiety
Parents need to know that infants as young as 4 to 5 months of age may be anxious when they are separated from their parents, to meet strangers or even familiar relatives. Even grandparents need to allow the infant to warm up to them before taking the infant from the mother. This anxiety peaks about 8 months. This is not a reaction but a normal developmental phase. Providing time for the infant to get to know a new caregiver in the presence of the mother, before separation, is critically important. There must be consistency in this relationship. Transitions will be easier if a child is encouraged to have a special stuffed animal, blanket, or similar favorite object, which she holds on to as an important companion.
Bright Futures Resources and Toolkit (2010)
Developmental Surveillance and Screening Algorithm Within a Pediatric Preventive Care Visit

1. **Pediatric Patient at Preventive Care Visit**
2. **Perform Surveillance**
3. **Does Surveillance Demonstrate Risk?**
   - Yes: **Administer Screening Tool**
   - No: **Schedule Next Routine Visit**
4. **Is this a 9-, 18-, or 24-36-month visit?**
   - Yes: **Administer Screening Tool**
   - No: **Schedule Next Routine Visit**
5a. **Are the Screening Tool Results Positive / Concerning?**
   - Yes: **Make Referrals for: Developmental and Medical Evaluations & Early Developmental Intervention / Early Childhood Services**
   - No: **Visit Complete**
5b. **Administer Screening Tool**
6a. **Return Visit**
6b. **Are the Screening Tool Results Positive / Concerning?**
   - Yes: **Make Referrals for: Developmental and Medical Evaluations & Early Developmental Intervention / Early Childhood Services**
   - No: **Visit Complete**
7. **Organizational Evaluation & Follow-up Visits**
8. **Increasing Developmental Concern**
9. **Is a Developmental Disorder Identified?**
   - Yes: **Identify as a Child with Special Health Care Needs / Initiate Chronic Condition Management**
   - No: **Visit Complete**
10. **Visit Complete**
Vendor Consortium

- Investigate ways to partner with the vendor community to distribute AAP knowledge and expertise in an electronic format that can be linked to, or embedded within and EHR

- 11 Vendors in attendance
  - Small and large systems
  - Varied levels of knowledge about AAP Content
Content Preferences

- Bright Futures
  - Prioritization/customization is needed
  - Rank content from most to least important
  - Recommends assembling BF into different combination sets
  - In translation, include branching logic to determine next action step in decision tree
Vendors want content delivered in multiple formats to allow for flexibility in the development and delivery

- If then statements
- Algorithms
- Web services
- Protocol templates
- Pseudo-code recommendations
Translation of Bright Futures

- Creation of web service software
- Translation of Bright Futures Content
- Development of a concept library
- Arrangement of hosting process
How would the web service work?
Newborn Metabolic Screening

Title: Universal Newborn Metabolic Screening Assessment;
Filename: TBD;
Version: 0.1;
Institution: American Academy of Pediatrics;

Library:
Purpose: Universal newborn screening is an essential public health responsibility that is critical for improving the health outcomes of affected children. /* This is from the Bright Futures guidelines. */;

Explanation: Checks for evidence of newborn screening. If not done, recommends performing test.;
Keywords: newborn screening reminder screening universal;
Links: http://brightfutures.aap.org/;

Knowledge:
Type: data_driven;
Data:
DOB := Read (DOB from EHR);
LastNewbornMetabolicScreenDate:=Read Last(TestDate from EHR) where LOINC = 57794-0;
LastNewbornMetabolicScreenResult:=Read Last(TestValue from EHR) where LOINC = 57794-0;
ScheduledProcedures:= Read (CPT from EHR) where it occurred in the past 30 days;
Priority: 1;
Evoke: On registration HL7 ADT;

Logic:
If  (TODAY - DOB) >= 6 months) then conclude false;
If 
[(LastNewbornMetabolicScreenResult <> "Inadequate") AND
Exists(LastNewbornMetabolicScreenResult)/* There is a valid newborn screening result */ then conclude false;
If (**CPT for Newborn Screening Order** is in ScheduledProcedures) then conclude false;
Else conclude true;

Action:
Write ("The AAP recommends performing a newborn metabolic screening test for children 0 -<3 months old.");

/*? leave this out*/ Read (Newborn_Screening_Order, CPT=???)

end:
Preliminary Implementation Plan

- Market: Electronic Health Record Vendors

- Consult out for the translation of Bright Futures content and creation of web service software

- Establish a committee involving pediatricians, pediatric informatics experts, knowledge management experts and Bright Futures content experts to manage content maintenance

- Establish a relationship with a web service provider for ongoing hosting
HL7’s 26th Annual Plenary Meeting

mHIMSS Overview and Standards Development

transforming healthcare through IT™
The Public Embraces Mobile Computing
Smart Phone Adoption
U.S. Smartphone Market Share by OS Expanded Trend

Source: comScore MobiLens, 3 mon. avg. ending Dec-2005 to Dec-2011, U.S.
Tablets & Smartphone's in Healthcare Delivery

- Apps tap into existing hospital IT infrastructure, showing real-time data on a hospital patient and improving daily workflow
- One third of the doctors surveyed listed privacy and security as their chief barrier to using mobile health issue

Tablet Adoption by Physicians

• More than 30% of physicians use tablet devices, compared to 5% of U.S. consumers

• 20% of physicians use their tablets in clinical settings

• 65% of respondents indicated that they are likely to use a tablet within the next few years to help their practice

• Resource: Frank Irving “Study Shows Surge of Tablet Use Among Physicians” govhealthit.com
### Number of Health Apps on the Rise

<table>
<thead>
<tr>
<th>Application</th>
<th>Number of health applications available for download</th>
<th>Intended for consumer/patient</th>
<th>Intended for healthcare professional</th>
<th>Number of downloads</th>
</tr>
</thead>
<tbody>
<tr>
<td>iPhone</td>
<td>~6000</td>
<td>73%</td>
<td>30%</td>
<td>Unknown</td>
</tr>
<tr>
<td>Android</td>
<td>~600 Number of Health Apps on the Rise</td>
<td>81%</td>
<td>20%</td>
<td>3.5 million +</td>
</tr>
<tr>
<td>Blackberry</td>
<td>~200</td>
<td>70%</td>
<td>30%</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

Resource: mobihealth.com
Medical App Types

% of iPhone Apps that Represent Medical, Health or Fitness

- Medical Reference: 50%
- Other: 12%
- Miscategorized: 12%
- Med Calculator: 9%
- EHRs and Ops: 7%
- Prenatal/Infant care: 3%
- Chronic Disease: 3%
- Emergency Info: 2%
- 1%

Transforming Care Models

• Mobility brings order and chaos...opportunities and challenges

• Changes the patient - health care provider relationship
  – Services once available only at a provider location will become available on demand at the patient’s location through low tech affordable solutions

• Changes when and how data is accessed and used
  – Right data, right time, right place
Wireless Sensors in the Home
Transformative Opportunities:

*Right data, Right time, Right place*

- Point-of-care delivery & workflow enhancements
- Smart phones & VoIP augment communications
- Telemetry & wireless IV pumps
- Connectivity to HIE & other care providers
- Mobile medication management
- Remote monitoring & diagnostics
- Engaged consumers & care providers
- Access to Health Disparate populations
Integration Challenges:

- Workflow
- Privacy & Security
- Infrastructure & Interoperability
- Reimbursement
- Consumer & care providers demand
- Regulatory Requirements
  - Federal, State, Local and Institutional
  - FDA & FCC RF wireless & medical App guidelines for HC
- Spectrum capacity & allocation policy (US)
Problem Statement: The exceptional promise of mobile health’s ability to improve access, outcomes and control costs will not be realized because the sheer magnitude of mobile options is overwhelming existing operations, infrastructure, security, policy, legal, and integration capabilities of the US and global healthcare systems.
mHIMSS Initiative Goal

- Goal Statement: Over the next five years, all stakeholders will embrace and harness the power of mobile technology to improve access, health and control costs, transforming healthcare in the USA and globally.
Health Stakeholders

- NIH, PEW, AHRQ
- National Academies
- HIMSS Analytics
- Universities, I2 & NLR
- R&D Telecom & Pharma

- Congressional
- State & local
- ONC, FDA, FCC
- Department of Commerce

- ACT, ATA, TIA, CTIA, Continua, Health 2.0, West Wireless, mHealth Alliance, SHLBC, I2, GSMA, WLSA, FNIH, NIH

- Patient advocacy groups
- Consumer groups
- Not-for-profits
- Clinical Research / Pharma – CTIS, CEA

- Telecom Infrastructure
- Health IT
- Mobile Apps & vendors
- Device manufactures
- Security Technology Vendors
- RTLS/RFID vendors

- Payers – CMS & Private
- Industry & Federal Leases
- OECD, WEF
- Venture Capital
- Federal Grants/Subsidies-BTOP
- mFinance & Revenue Cycle

- Hospitals & Providers
- Federal Health – DOD, VA, TATRC
- Public Health & FQHCs
- Lab/Pharmacy
- CAIs
- EMS Community

- HIMSS, CHIME,
- AMA, AHA, ATA, ACCE,
- AMIA, AHIMA, MGMA,
- HCTAA, Rural & Hospice

- NIH, PEW, AHRQ
- National Academies
- HIMSS Analytics
- Universities, I2 & NLR
- R&D Telecom & Pharma

- ISO, I TU, ANSI,
- NIST, ONC,
- IEEE, MITA, WiFi Alliance

- Federal Agencies
- Technology
- Finance
- Academia & Research
- Standards Development Organizations
- Policy
- HC Industry Organizations
- Clinical Providers
- Patient/Consumer
- Telecom Community
- Federal Agencies
- Technology
- Finance
- Academia & Research
- Standards Development Organizations
- Policy
- HC Industry Organizations
- Clinical Providers
- Patient/Consumer
- Telecom Community
# mHIMSS Focus

## Mobile Trends
- Emerging, Common & Best Practices
- Apps
- Health Care Professionals & Mobile Health IT
- Consumers & Mobile Health IT

## Mobile Topics
- Privacy & Security
- Standards, Interoperability, Data Exchange
- Implementation, Infrastructure & Device Management
- Usability, Accessibility, Human Factors & Design

## Mobile Matters
- Policy
- Grants, Research & Governmental Mobile Health Initiatives
- Health Disparities
mHIMSS Structure

- Advisory Council
- Corporate Round Table
- Taskforce
  - Workgroups
    - Mobile Device Functionality
    - Mobile FAQs
    - Case Studies
    - Mobile Blog
    - Policy
    - What’s Next?
    - Health Disparities
mHIMSS Resources

- [www.mhimss.org](http://www.mhimss.org)
- Mobile Book
- [HIMSS Analytics Mobile Survey](http://www.mhimss.org)
- *mHIMSS App*
- JHIM Mobile Issue Summer 2012
Midmark touts clinical, financial benefits of home sleep testing solution
Midmark, a medical device manufacturer, recently announced the benefits of its new home sleep testing solution. The company claims that this technology offers significant cost savings compared to traditional in-clinic sleep studies.

mHealth Summit Issues call for proposals
The upcoming mHealth Summit, scheduled for September 30-October 2, 2012 at the Gaylord National Resort in National Harbor, MD, is calling for proposals for its keynote sessions, breakout panels, and workshops. Deadlines and submission instructions can be found on the summit's website.

New analysis sees growth in home health monitoring market— with the patient as the customer
A new analysis by Frost & Sullivan predicts that the home health monitoring market will grow by 12.5% per year through 2016, driven by increasing patient ownership and adoption of technology. The report also highlights the importance of engaging patients in their own care.

Call for Presentations Now Open for 2012 mHealth Summit
The largest event of its kind, the 4th annual mHealth Summit brings together leaders in government, the private sector, academia, providers and not-for-profit organizations from across the mHealth ecosystem to advance the future of mobile health. This year’s event, scheduled for September 30-October 2, 2012 at the Gaylord National Resort in National Harbor, MD, is now accepting presentations.

TOOLS & RESOURCES
- Case Studies
- Research
- Webinars
- Tools & Topics
- Video

The Future of Mobile Technologies and mHealth: Staying Securely Connected
While mobile technology is transforming healthcare, ensuring patient privacy and data security remains a top priority. HIMSS provides resources and guidelines to help healthcare providers navigate these important issues.
Emerging Mobile Standards

• IHE IT Infrastructure
  – Documents for Mobile Health (MHD)

• ONC S&I Framework
  – RHEX Project
  – Auto-Bluebutton (ABBI)

• OMG/Mitre
  – hData
Documents for Mobile Health (MHD)

• IHE Profile Proposed last September

• Two Use Cases:
  – download Metadata & Documents
  – Upload of a Single Document

• RESTful Protocol

• JSON

• Aligned with OMG/HL7 hData Efforts
ONC Projects

• RHEX Project Announced 6/7
  – Promoted as “Web 2.0 for Health”
  – See http://wiki.siframework.org/RHEX

• Auto Bluebutton (ABBI)
  – Discussed at Patient Access Summit
  – Constant access to patient data, via push or pull
  – http://wiki.siframework.org/Automate+Blue+Button+Initiative
hData Overview

• hData was originally developed by The MITRE Corporation
  – Internal R&D
  – Focus on simplifying Continuity of Care use cases
  – Broad initial goal set:
    • Wire format simplification
    • Strict data modeling and content separation from exchange mechanics
    • Flexible metadata model
    • Transport simplification
    • Patient-centric identity management and access control
• Significant interest from XML, health IT, and government communities
hData goes Standard

• To improve quality and adoption, hData pursued standardization
  – Health Layer 7 (HL7) and Object Management Group (OMG)
  – Part of Service-Oriented Architecture catalog of standards
    • Realization of Resource Locate and Update Service (RLUS) Functional Model
    • REST Binding established Resource-Oriented Service approach
  – Limited scope for initial set of standards
    • Packaging and meta-data (HL7)
    • REST Transport and RLUS realization (OMG)

• Current status: Draft/Beta Standards (Q1CY2012)
Questions?
Thank you!

Jim St.Clair
Senior Director, Interoperability and Standards
(312) 915-9590
jstclair@himss.org
Consumer’s and the future....

Aren’t you already doing that.....
What consumers want ...
Australian Health Consumers

• Consumer Health Forum
  – Educates consumers
  – Provides representatives
  – Research centre for consumers
  – Resource for consumer representatives
Consumer representatives

Photo: http://trevorsbirding.com/large-flock-of-gal bahs/
Consumer representatives

• Access to real world stories
• Represent real people
• Integrated into decision making and governance structures at all levels of government
• Reporting and sharing – expertise and stories together
• Bring together disparate views
Health consumers have changed..

<table>
<thead>
<tr>
<th>10 years ago</th>
<th>Today</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afraid of technology</td>
<td>General belief that it’s already happening</td>
</tr>
<tr>
<td>No idea of benefits</td>
<td>Long list of benefits desired</td>
</tr>
<tr>
<td>Strong idea of risks</td>
<td>Risks acknowledged – need for balance Don’t make it worse</td>
</tr>
</tbody>
</table>
Empowered consumer

- Partners in the process (including standards)
  - Input that is used and listened to
  - Information to support decisions
  - Ability to control what is shared

Photo: H. Grain
The demand

• It doesn’t have to be perfect, it does have to be better....
• It mustn’t take away the controls we have now... (we choose what to share)
• Recognise our value as a treatment team member (and the risk if we aren’t on board)
• Standards that consider the real world needs
Why not?

• Not all consumers know what they are doing and understand the implications of their actions
• Not all consumers are honest
• Not all consumers want to know

Do we build systems and standards for the Nots, when we could build for the Dos and make a real difference.

Photo: H. Grain
Healthcare is not a greenfield site..

- Do we
  - Preserve what we have and not move forward
Healthcare is not a greenfield site..

- Do we
  - Destroy what we have in order to move forward

Photo: H. Grain
Healthcare is not a greenfield site..

• Do we
  – Seek a middle ground with the best of both

Photo: H. Grain
Please rate the quality of the presentations by check marking your response for each question, for each speaker:

<table>
<thead>
<tr>
<th>INDIVIDUAL PRESENTATIONS</th>
<th>Excellent</th>
<th>Very Good</th>
<th>Acceptable</th>
<th>Not Acceptable</th>
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<tbody>
<tr>
<td>KEYNOTE SESSION 1 – Engaging Patients with Standards</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leslie Kelly Hall</td>
<td>Content of Session</td>
<td>Delivery by Speaker</td>
<td>Usefulness of Information</td>
<td>Visual Aids</td>
</tr>
<tr>
<td>Senior Vice President, Healthwise</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>KEYNOTE SESSION 2 – The Rise of e-Patients</td>
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</tr>
<tr>
<td>Lee Rainie</td>
<td>Content of Session</td>
<td>Delivery by Speaker</td>
<td>Usefulness of Information</td>
<td>Visual Aids</td>
</tr>
<tr>
<td>Director, Pew Research Center’s Internet &amp; American Life Project, and formerly the managing editor of the news magazine U.S. News &amp; World Report</td>
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<tr>
<td>KEYNOTE SESSION 3 – Consumer Empowerment</td>
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<tr>
<td>Elaine A. Blechman, PhD</td>
<td>Content of Session</td>
<td>Delivery by Speaker</td>
<td>Usefulness of Information</td>
<td>Visual Aids</td>
</tr>
<tr>
<td>Professor Emerita, University of Colorado-Boulder and President, Prosocial Applications</td>
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</table>

Panel discussion featuring presentations from different stakeholders in the mobile health space on how they view the future of mobile health and HL7’s potential role in this evolving arena – Moderated by Doug Fridsma, MD, PhD: Director, Office of Standards and Interoperability, Office of the National Coordinator for Health IT

<table>
<thead>
<tr>
<th>Delivery by Speaker</th>
<th>Usefulness of Information</th>
<th>Visual Aids</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chuck Parker</td>
<td>President, Continua Health Alliance</td>
<td></td>
</tr>
<tr>
<td>Christoph Lehmann, MD</td>
<td>Professor of Pediatrics and Biomedical Informatics, Vanderbilt University, will discuss empowering families of children</td>
<td></td>
</tr>
<tr>
<td>Jim St. Clair</td>
<td>Senior Director, Interoperability and Standards, HIMSS</td>
<td></td>
</tr>
<tr>
<td>Lonnie Smith</td>
<td>Policy Analyst, U.S. Food and Drug Administration (FDA), will discuss mobile applications of SPL.</td>
<td></td>
</tr>
<tr>
<td>Heather Grain</td>
<td>Standards Australia</td>
<td></td>
</tr>
</tbody>
</table>

-- Over --
### Speaker & Session Evaluation Form

<table>
<thead>
<tr>
<th></th>
<th>Excellent</th>
<th>Very Good</th>
<th>Acceptable</th>
<th>Not Acceptable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall satisfaction of Plenary topics and content?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The overall delivery of the presentations?</td>
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<tr>
<td>The usefulness of this information?</td>
<td></td>
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<td></td>
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<tr>
<td>The visual aids/handouts?</td>
<td></td>
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</tbody>
</table>

**Comments & suggestions on any of the presentations would be appreciated!**

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**What specific topics and/or speakers would you like to see at future HL7 Plenary Meetings?**

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*Please take a moment to complete this Plenary Meeting evaluation form. Thank you!*