

O'Reilly Open Source Convention:

Report on the
Health Care Track

by Andy Oram, O'Reilly Media

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The O'Reilly Open Source Convention (OSCON), introduced a health care track for the first time in 2010. The track was inspired by O'Reilly Media's growing interest in the innovations coming out of the intersection of healthcare and technology, was constructed using research and connections to health care innovators built by Tim O'Reilly and other O'Reilly staff, and was sponsored by the Robert Wood Johnson Foundation. When putting out the Request for Proposals and advertising the track, O'Reilly promoted it as an opportunity for speakers and their audience to connect around the following issues:

- The value of open source software in health care, to spread the benefits of technology to under-served regions and to preserve and allow the interchange of useful health-related data
- The uses of electronic health records for data exchange, quality improvement, and cost savings
- Patient-centered medicine and modifications in daily behavior
- The use of mobile devices to collect and disseminate information
- The value of standards to allow exchange and research-related manipulation of health care data

It is not surprising that the submissions reflected these priorities as well. Out of 33 proposals submitted, a series of 22 were chosen that included project leaders of the major open source electronic health records (EHR) projects, leaders of the Administration's health care agenda at the U.S. Department of Health and Human Service's Office of the National Coordinator (ONC), speakers from Microsoft's and Google's health care projects, and many others working at the forefront of quality improvement and a greater role for the patient in health maintenance. This summary of the OSCON Health Track identifies the themes that emerged over the course of three days of sessions and discussions and highlights key takeaways from individual sessions.

Themes of the conference

Several points were raised repeatedly by many speakers and formed a set of lessons to be taken from the health care track as a whole.

The need for radical change

There is no argument over the problems facing the American health care system. Its costs have risen to about 20% of the entire output of the American economy and will continue to skyrocket unless solutions are found. Perhaps a third of medical procedures are unnecessary.

Quality is also a problem. Although many more conditions can be cured during recent decades and some treatments verge on the miraculous, we also have a large segment of the population that can't afford regular access to a doctor, while other parts of the world simply don't have the staff and facilities to offer help. A number of studies show that 100,000 Americans die each year because of medical errors. Another group of that size may be the victims of iatrogenic infections.

Involving the patient in his or her care

Improvements in diagnosis, drugs, and surgical procedures have reduced the incidence of many diseases and acute symptoms, leaving chronic conditions as the chief source of distress among people in economically advanced countries. This trend combined with aging has shifted the requirements of the health care field from one-time interventions to long-term involvement with the patient, a shift that most of the American health care industry has failed to make. The patient is also more and more responsible for his or her own health through Observations of Daily Living and life-style choices, a shift requiring extensive education and support.

Data sharing and evidence-based medicine

To find the best treatments, a new kind of research is called for beyond complex double-blind experiments. Many valuable interventions have been discovered through longitudinal statistical collection over large populations, as epidemiologists do. Such data collection requires the entire health care field—patients, doctors, hospitals, insurers, and government agencies—to ramp up quality control on many levels: the collection of data; the free-flowing sharing of de-identified data; the use of sophisticated statistical techniques to find patterns; and the dissemination of recommended practices through easy-to-use software interfaces. Current systems that lock up data in proprietary formats, exchanging only the minimum number of fields required by laws or standards, will not meet our needs. Open data formats and secure, well-established software protocols for data exchange are a necessity.

Privacy concerns

Patients will not tolerate the use of electronic systems and the release of data unless they feel assured that their health data will stay out of the wrong hands. Concerns are heightened as people hear of new statistical techniques that can combine different facts to associate supposedly de-identified data with an individual, the most famous example being a 1997 experiment by CMU researcher Latanya Sweeney that revealed private facts about the governor of Massachusetts. Software architectures will have to evolve to ensure privacy.

Open source

Not surprisingly, given the conference focus, many of the themes that emerged pointed to the importance of open source software. Most of the speakers were fervent advocates for its use in health care, having come to that conclusion by observing the benefits it offered in contrast to proprietary software. Open source software was praised for:

- Simplifying data exchange and ensuring that data will still be available decades from now through open data formats
- Creating systems in tune with health care providers' needs, because the providers are involved in the systems' creation from the start
- Bringing the most advanced electronic systems within the reach of institutions with limited funds
- Enhancing security and privacy by exposing software to expert evaluation

Organizational and cultural change

The various innovations described so far cannot merely be packaged up and delivered to health care providers to effect change. The providers must be willing to subject their workflows, attitudes, and routines to criticism. For instance, Farzad Mostashari, Senior Advisor at the Office of the National Coordinator for Health IT in Health and Human Services, stated before the Senate Special Committee on Aging on April 22, 2010: "It is clear that the outcomes achieved by the VA and Group Health were not the result of simply purchasing and deploying telehealth or mobile health tools, but were due to the thoughtful pairing of emerging technologies with new care delivery processes."

Individual sessions

This section will highlight interesting points made in particular sessions, providing some background to show their value.

Opening remarks

Tim O'Reilly (affiliation: O'Reilly) and Deborah Bryant (affiliation: OSU Open Source Lab)

O'Reilly summarized several of the themes, especially patient self-monitoring and data sharing. Bryant laid the groundwork for upcoming speakers on NHIN and CONNECT, and discussed the importance of open source projects creating communities of developers in order to remain sustainable.

Health of the Source

Fred Trotter (affiliation: Cautious Patient)

Trotter laid out the stakes in health care and tied in the importance of open data and open source. He said we've reached the limit of what we can achieve through clinical efforts; major advances at this point will require close collaboration between health care professionals and patients, who must be informed and empowered. Furthermore, we must understand better what produces and preserves health, which requires the collection and dissemination of high-quality data.

Proprietary health records lock up data. Any data exchange requires cumbersome efforts on the part of the vendor and often the holder of the data. The risk is great that data being stored in electronic records will eventually be totally lost because vendors go out of business or change formats and stop supporting old formats, as has happened in many other software industries.

Open source is therefore important not only to bring the cost of electronic records within the means of all health care providers, but to allow the next wave in quality control and patient-centered medicine to move forward.

Open Source's Role in CONNECTing the Public and Private Sector Healthcare Communities

David Riley (affiliation: Federal Health Architecture, Office of the National Coordinator for Health IT, Department of Health and Human Services) and Brian Behlendorf (affiliation: Federal Health Architecture (FHA) program in the Office of National Coordinator for Health Information Technology within the Department of Health and Human Services (HHS))

These contractors coordinate the open source development of CONNECT, the current implementation of the data-sharing system known as the National Health Information Network. NHIN began as a way for federal agencies to securely share health care data, reflecting the requirements such data present for authentication of requests and other measures to protect privacy. However, after developing CONNECT, HHS realized that NHIN would also be valuable for hospitals to report required data back to federal agencies, for health care providers to exchange data in order to facilitate referrals and other shared patient care, and eventually for health care providers to communicate with patients. Thus, CONNECT became a public project and has received numerous contributions from a wide range of volunteers.

Riley laid out the architecture of CONNECT and features planned for upcoming releases. He announced that requests between agencies for health care data have gone from months to minutes with CONNECT. It is currently based on SOAP, an XML-based technology that has been proven in use at large institutions and provides reliable security but is not as widespread as popular current web technologies such as REST. CONNECT is

being refactored so that in the future it can run over REST, XMPP, and SMTP (the Internet mail protocol). The SMTP implementation will be particularly congenial to small health care providers with little technical know-how whose main digital communications are electronic mail.

NHIN Direct: An Open Government Health IT Collaboration

Arien Malec (affiliation: HHS/ONC (Contractor))

Malec contrasted health care before the middle of the twentieth century with modern health care based on the advances of science. Early doctors knew their patients well and followed the longitudinal course of their syndromes and diseases. Of course, the early doctors had few tools to actually intervene and fix the problems. Later doctors were blessed with cures that could appear near-miraculous, but specialization led to an episodic approach to health care. We have to use health records and modern data mining to restore the longitudinal, holistic view of the patient. Our health care systems need to remember us. NHIN is one of the foundations for such uses of health data.

Taking OpenEMR, a GPL EMR to ARRA Meaningful Use Certification and beyond

Tony McCormick (affiliation: Medical Information Integration, LLC) and Samuel Bowen, MD (affiliation: Open Source Medical Software)

McCormick and Bowen presented the first in a series of talks about the leading open source contenders for EHR systems. McCormick is a project leader on the openEMR project, while Bowen led a team that installed openEMR at a hospital.

Because doctors will seek the reimbursements that HHS offers for what it defines as “meaningful use” of electronic records, and because these are universally recognized as beneficial for patient health and cost control, the developers of electronic health record sys-

tems must support the meaningful use criteria. McCormick and Bowen estimate that the openEMR team, bolstered by both paid contractors and volunteer contributions, has implemented about 80% of the required functionality.

Project leaders also went to Washington and argued with government staff to change meaningful use requirements that would have essentially made it impossible for open source projects to meet them. One of the key provisions of the requirements, for which the open source advocates may well have been responsible, allowed EHR providers to certify modules instead of entire stand-alone systems.

Leveraging Open Source Software to Assure Privacy of Health Information

Thomas Jones (affiliation: Tolven)

Jones’s talk centered on privacy, but with a perspective including broader issues of patient-centered medicine. Tolven supports both records held by the doctor (clinical health records) and records held by the patient (personal health records).

In a system designed especially for the Netherlands—where privacy laws are much stricter and better specified than in the United States—Tolven stores medical records in large, centralized repositories to facilitate security. Data is encrypted during both transmission and storage, and only the patient has the key to unlock it. Audit trails add another layer of protection.

This architecture obviates the need for release forms. Instead, the patient explicitly approves every data transfer. Patients can designate special repositories to which their relatives have access, in case of emergencies when they’re not competent to make the transfer.

Tolven represents an important trend in electronic health records away from systems installed at the doctors’ offices—and therefore requiring expert help for installation and upgrades—toward Software as a Service, where the system’s developers or another official institution maintain the software and provide it over the Web.

Human Resources Information Systems (HRIS) for Health in Low-Resource Settings

Carl Leitner (affiliation: IntraHealth International)

IntraHealth International operates in many Sub-Saharan and South Asian countries, offering software to help manage one of their most precious and dwindling resources: health care professionals. Their system, called iHRIS, lets individual hospitals as well as whole nations determine where their most pressing staffing needs lie, break down staff by demographic information such as age and gender (even language), and track their locations. Such information can also expose graft.

Open source is critical for a system like iHRIS, not just because funds are scarce, but because localization is critical. Lots of languages whose very existence is unknown to proprietary vendors need to be supported. Each country also has different regulations and on-the-ground conditions.

IntraHealth International holds regular unconferences, mentoring, and other forms of training in its target countries in the hope of (in Leitner's words) putting themselves out of business.

DIY Genomics: an open platform for citizen science

Melanie Swan (affiliation: DIYgenomics)

The DIYgenomics company lets patients who have undergone consumer-level DNA sequencing share data in order to help researchers discover patterns that can improve responses to disease. From a research point of view, DIYgenomics provide preliminary data that suggests directions for future research. DIYgenomics also provides general research results to consumers.

Swan characterized DIYgenomics as part of the open science movement and suggested that, for many rare health conditions, its crowdsourced approach can fill a gap that professional researchers won't fill.

She summarized the first two generations of DNA sequencing and reported that we are on the verge of a third generation that could bring full genome sequencing down to an affordable level.

DIYgenomics is currently conducting two longitudinal studies: one for people who do not absorb vitamin B12 properly, and another on aging.

Distributed, Modular Grid Software for Management and Exploration of Data in Patient-Centric Healthcare IT

Andrew Hart (affiliation: NASA Jet Propulsion Laboratory), and David Kale (affiliation: Children's Hospital Los Angeles)

With the unlikely help of the Jet Propulsion Laboratory, several medical research projects, including one at Children's Hospital, are finding better ways to share and mine health data. The JPL faced a problem of having to tie together many different projects with different management teams, each storing data in different formats in different databases. This led to a software architecture called the Object Oriented Data Technology (OODT) framework, which is now in the well-established open source Apache incubator.

The system has to be able to translate between formats seamlessly so that researchers can quickly query different sites for related data and combine it. Part of the solution is to define a data model for each type of data and to put software at each site to translate between data models. A routing layer searches for appropriate data stores to supply requested data, while identity services allow sites to control whom they share data to.

Children's Hospital is currently building a large research database with the help of JPL. No research results are available yet.

The VA and VistA: A Role Model for Radical Improvement of Health Systems Everywhere

Phillip Longman (affiliation: New America Foundation)

Longman summarized the fascinating history of the Veteran Administration's quality control efforts, carried out through its open source VistA software as detailed in his book *Best Care Anywhere* (PoliPoint Press). He argued not only that these successful efforts show the way forward for other institutions to improve health care and lower costs, but that the VistA software and the VA's evidence-based procedures should be offered as a system for other health care providers to adopt.

Because of indifference and frequent hostility from VA management in the 1970s and 1980s, VistA developed in a decentralized fashion. This ended up creating a system that met the needs of doctors and other health care professionals more than proprietary, commercial medical systems because the professionals were directly involved in VistA's creation.

vxVistA.org Community Collaboration Web Portal Uses Atlassian Open Source Web Tools to Deploy vxVistA-OS EHR

Deanne Clark, Hugh Creedon, and J.D. Keith (affiliation: DSS Inc.)

The speakers explained vxVistA.org's strategy for spreading the adoption of VistA among private health care providers. They chose several closed-source tools from Atlassian (notably the well-known Confluence) to provide a platform for development, finding that these tools would improve programmer productivity and allow a community to communicate better. They also closed their version of VistA for a few years and worked on it to iron out bugs in order to make sure they had a well-integrated, unified product so that early adoptions would go well. Their version of VistA is now under an open license.

Introduction to Open Source VistA EHR

K.S. Bhaskar (affiliation: Fidelity Information Services, Inc.), Ben Mehling (affiliation: Medsphere Systems), and David Whiles (affiliation: Midland Memorial Hospital)

The speakers mentioned a number of successful adoptions of VistA in public and private institutions around the U.S. and the world. K.S. Bhaskar provided a completely open-source version of VistA's MUMPS language and database, making it unnecessary for sites to contract with the commercial Cache database.

Google Health: Connecting Mobile Patients

Roni Zeiger (affiliation: Google)

In one of the best-attended talks, Zeiger explained the importance of tying Observations of Daily Living into each person's health record. He showed off some intriguing, sometimes jerry-rigged devices that measure a range of health-related statistics and transmit them to Google Health's personal health record for storage.

Examples included:

- An app that uses GPS to show your path during a run
- An app uses the accelerometer to show changes in elevation during a bike ride
- An inhaler that collects information on where and when people have asthma attacks

The ultimate goal is to feed such data into doctors' health record systems so they can respond with useful advice. This would require doctors to set up electronic systems that can accept such information on a regular basis.

Building the Redwood MedNet HIE with Mirth Open Source Tools

Will Ross (affiliation: Redwood MedNet), and Gerald Bortis (affiliation: Mirth Corporation)

This talk returned to the subject of CONNECT, the software that allows secure patient data exchanges among health care institutions. Will Ross described a project to connect health care providers across a mostly rural county in California. The open source solution offered by Mirth Corporation proved to be the only one they could afford. Mirth provides tools for extracting data from structured documents as well as exchanging it.

Using Open Source Technologies to Deliver a Healthcare Interoperability Platform that Improves Medical Outcomes and Enables Public Health Surveillance

Nagesh Bashyam (affiliation: Harris Corporation)

Bashyam is the Chief Architect for Harris Healthcare Solutions, which is the prime contractor for CONNECT. He reiterated how CONNECT can lead to more than data exchange—it can let a doctor combine information from many sources and therefore be a platform for value-added services.

Modernizing VistA, ClearHealth's Invaluable Lessons from 'Legacy' Technology and Ways Forward

David Uhlman (affiliation: clearhealth inc.)

In his first of two talks for this conference, Uhlman gave a compelling overview of VistA's history, and asserted that nearly everything in the current "Meaningful Use" criteria was already implemented thirty years ago by the VA, through VistA.

The Project HealthDesign Common Platform: Enabling Innovative Uses of Health Data by Personal Health Applications

Sam Faus (affiliation: Sujansky & Associates, LLC)

Faus discussed the health care projects sponsored by the Robert Wood Johnson Foundation and explained his own task of tying these together. His Common Platform had to create many standards from scratch, because no one had defined data models before for Observations of Daily Living (ODL). The Common Platform continued even after Google Health and Microsoft Health Vault were announced.

Therefore, there are several emerging standards for ODL, measuring different things and organizing them in different ways. Faus said this is a reasonable state of affairs because we are so early in the patient-centered movement.

Free Software on Medical Devices: Unchain My Heart

Karen Sandler (affiliation: Software Freedom Law Center)

Sandler, a lawyer from the Software Freedom Law Center, pointed out that hundreds of thousands of devices—pacemakers, insulin delivery devices, defibrillators, and others—are implanted in people's bodies each year. These devices fail sometimes, and software flaws are often suspected. They are also subject to malicious manipulation, because manufacturers avoid encryption in order to spare the device's battery.

She called for publishing the software used in devices for auditing purposes, and even held out the idea that the users of these devices could have the hardware and software altered along open source principles. The talk, based on both research and personal experience, drew a sizeable audience and excited a good deal of sympathy.

Programming Healthcare Silos

Vaibhav Bhandari (affiliation: Microsoft, Health Solutions Group)

Bhandari gave the audience a feel for standards in the health care field by displaying some sample records. Each format tends to be idiosyncratic, using an ad hoc data model and various arbitrary punctuation characters to set off fields, although a move toward XML is gradually taking place. He also showed a few of the libraries that Microsoft HealthVault uses to make standards useful ways to store and manipulate health data.

Advancing Interoperability, Patient Safety, and Efficiency with the Microsoft Connected Health Platform Open Toolkits

Teddy Bachour (affiliation: Microsoft)

Bachour showed the use of Microsoft toolkits for manipulating health care data. As an example of what programmers can do with them, the Clinical Documentation Solution Accelerator enhances Microsoft Word so that as a doctor enters a report of a patient visit, Word can prompt for certain fields and offer a selection of valid keywords for such fields as diagnoses and medications.

Data Mining in the EMR Gold Rush

David Uhlman (affiliation: clearhealth inc.)

In his second session for this conference, Uhlman gave a dazzling talk that applied neural network analysis, genetic algorithms, visualization, and other tools to basic questions such as "How many of my patients are likely to miss their visits today?" and common tasks such as viewing multiple lab results together over time. This overview went to the heart of the tasks of health care IT: to take the mounds of new data that electronic records and Meaningful Use will generate, and find answers to everyday problems bedeviling practitioners.

Summary

Attendees and speakers declared the open source health care track a success. Audience discussion showed that it attracted sophisticated professionals from health care institutions, especially IT staff. Two well-attended Birds of a Feather sessions held informally in the evenings allowed health care leaders and conference attendees to meet and form relationships.

One gap must be acknowledged—the absence of established vendors in electronic health care records or other health care-related products. Not a surprising absence, as the Health Care track was part of Open Source Convention. But the striking divide between the progressive forces that were represented so well at the conference and the mainstream health care industry does substantiate the long path that open source health IT and other forward-looking measures—such as improved daily living through home monitoring, patient sharing in the DIY Genomics sense, and sophisticated data mining for quality improvement—must tread to be accepted among those who currently dominate the commercial health care technology ecosystem.

Over the course of three days, the OSCON Health Care track bolstered the cause of innovators by highlighting their hard-won successes, presenting from-the-trenches perspectives on using open source in health care, and providing a place for innovators to connect, tell their stories, share ideas, and build a network of change agents.