Office of the National Coordinator for Health IT
Interoperability and Health Information Exchange Workgroup
Governance Subgroup
Invited testimony 8/15/2014

Tim Burdick, MD, MSc, is a practicing family physician with 10 years of clinical informatics experience. He is providing comments today in his role as chief medical informatics officer at OCHIN. He also has academic appointments at Oregon Health & Sciences University (OHSU) in the Department of Family Medicine and the Department of Medical Informatics & Clinical Epidemiology, although he is not speaking on behalf of OHSU today.

OCHIN is a health center controlled network and has served as Oregon's Regional Extension Center, providing support for EHR adoption and meaningful use across multiple vendors since early 2010. Among our business lines, we host one shared EHR (Epic) across more than 80 independent healthcare organizations, mostly ambulatory care clinics within the nation's safety net. Our network presently spans more than 300 individual clinic sites in 22 states, with significant growth planned for 2015. We serve sites ranging from two-physician practices in rural communities to county health departments in large cities including Seattle, Washington (King County), and Portland, Oregon (Multnomah County). We use one, shared EHR with an enterprise-wide master patient index that enables sharing of healthcare information across all member organizations through an organized healthcare arrangement (OHCA). In addition to providing HIT support for clinical care and administrative transactions, OCHIN has a research department—an AHRQ-designated Practice Based Research Network that receives approximately $6 million per year in grant funding and has published more than 25 peer-reviewed articles about healthcare IT and utilization in the past two years. We are one of the first clinical data research networks funded by the Patient-Centered Outcomes Research Institute (PCORI) as part of PCORNET.

Responses to specific questions from the Governance Subgroup follow.

Portland Office:
1881 SW Naito Parkway, Portland, OR 97201
t: 503.943.2500 | f: 503.943.2501

Bend Office:
63026 Lower Meadow Drive, Suite 100, Bend, OR 97701
t: 541.585.2580 | f: 541.585.2581

www.ochin.org

Page 1 of 8 – 140813

1) What exchange use cases do you support? What challenges are inhibiting or slowing your ability to broadly deploy/support these use cases?

<u>Exchanges uses</u>: OCHIN is one of the leading organizations in the US for health information exchange health data transactions. We have more exchanges than any other Epic customer, using Epic's Care Everywhere. We share health information with a number of other organizations as well. For example, we are connected to the VA's Virtual Lifetime Electronic Record for C-CDA exchanges, and we share information with the US Social Security Administration to expedite their reviews and processes. From Redwood MedNet, Santa Cruz HIE, Healthbridge, North Carolina HIE, and other regional HIEs, we receive unsolicited and solicited lab results, radiology summaries, discharge summaries, admission and discharge data, continuity of care documents, and immunization data, all as structured/unstructured data. OCHIN has extensive experience maintaining over 30 bidirectional laboratory interfaces in many states including those with companies like Quest Diagnostics, LabCorp, and regional or community hospital laboratory facilities. Like most EHRs, we send prescription orders to thousands of pharmacies daily using Surescripts. For Meaningful Use Stage 2, we maintain outbound and, where permitted, bidirectional interfaces with 15 state immunization registries and a few state syndromic surveillance aggregators. We have also built a data warehouse with ingestion of data from 10 EHR vendors representing 32 separate EHR implementations, and we will soon be pulling in social determinants of health and other local, geospatial data. We are also expanding our patient portal, which includes the exchange of data (including provider visit notes) with more than 37,000 patients in approximately 30 states. We are in the infancy of the exchange of C-CDAs using Direct Messaging, and we will highlight some of the issues in implementation of Direct Messaging later in this report.

<u>Challenges</u>:

a) *Data are tethered to one EHR and to one patient portal.*

   <u>Example</u>: I met a patient recently who has advanced cancer. She accesses care from multiple providers in multiple organizations. The various EHRs remain isolated and unsynchronized. She can access some of her records online, but she must log into <u>six</u> separate portals. After each encounter, she sends messages to five other physicians requesting they update the data in their EHR. *We are pushing paper charts around the office using electrons rather than sharing data.*

b) *States lack shared technical standards.* Of the 22 states in which we operate, most have unique technical requirements around data exchange. The requirements are often outdated, vague, incomplete, impractical, and ever-changing.

   <u>Example</u>: In order to meet Meaningful Use Stage 2 Core Measure 16 (immunization registry), OCHIN had to build 15 different interfaces because each state had different data standards and exchange methodologies. Our annual cost just to maintain the current interfaces is more than $120,000. If there were one standard, OCHIN could build one interface to use in all 50 states, allowing us to focus our efforts on improving usability and clinical decision support.

c) *There is a diversity of interpretation of state/federal rules relating to data sharing.* In particular, we find that over-interpretation of CFR 42 Part 2 is constraining free movement of data/information/knowledge. This knowledge gap happens within a clinic, as well as between different treatment settings. In addition to CFR 42, many states have similar unique regulations

barring sharing data about substance abuse treatment, HIV status, and other sensitive PHI. Rather than treating all PHI as equally protected, some data are carved out, leading to difficulty in creating HIT systems that can work across state lines (and perpetuating stigmatization of certain diseases). Merely tracking the legislative requirements takes a full-time compliance officer.

Example 1: At one primary care clinic using OCHIN's EHR, a patient sees her clinical psychologist and her primary care physician. Their offices are in the same hallway, and they both have access to the same EHR. At one visit, the psychologist used a depression screening questionnaire, met with the patient for an hour, diagnosed moderately severe depression, identified multiple significant stressors, and documented the findings and treatment plan in a note. The PCP, at a visit with the same patient a week later, was unable to see any of the psychologist's notes, despite being colleagues in the same clinic. It turned out that the psychologist refused to document any of the findings in the EHR, using paper notes kept in a locked file cabinet, specifically citing CFR 42 as the limitation.

Example 2: OCHIN providers have agreed to share lab test results in real-time with patients via the patient portal. However, California has a unique law requiring a provider to review the results before patients have access, requiring OCHIN to reprogram our EHR for the CA-specific regulations. (Fortunately, only two states currently have unique portal regulations, and new federal legislation is likely to prevent further divergence of policies.)

d) *Payers, including ACOs, create their own unique quality reporting initiatives.* In many cases, the reports are based on metrics that vary slightly from national standards. This variation requires OCHIN report writers to create hundreds of queries to assess and report on the same quality measures.

Example: The State of California Medi-Cal Program requires extremely detailed reports for mental health treatment (Short-Doyle billing). Furthermore, the reporting is done at the county level, so OCHIN will need to create separate interfaces for each county. This one project alone will cost OCHIN more than $300,000—an expense that ultimately must be passed back to safety net clinics, paid out of their operating budgets, resulting in less direct patient care.

e) *There is a mismatch between cost and value of sharing data in some scenarios.* The Meaningful Use Stage 2 Menu Set Measure 6 (Specialized Registry) was one of the only Menu items OCHIN could reasonably build. However, in order to allow EPs in 22 states to meet the measure, we needed to build interfaces to 22 state registries or find one national registry. In reviewing our options, we found many "registries" that would accept our data on such terms as: data set includes PHI; each EP must pay $200/month; shared data can be sold or used at will. The return (reporting back to OCHIN with benchmarking or disease registry data) was very limited. In some cases, the registries are, behind opacity, run by pharmaceutical or medical equipment companies. Even if OCHIN found a suitable registry that added value, the cost ($200/EP/month for 4,500 providers) would be $10.8 million per year, more than one-third of our entire operating budget. The value is not there for OCHIN, the providers we serve, or their patients in the safety net.

2) What policy, trust, and technical requirements do you require be met before agreeing to exchange with another exchange service provider? What, if any, assurances do you require that your trading partners are adhering to these requirements?

OCHIN employs several standard <u>policies</u> regarding data sharing and security/privacy, depending on the use case. These mechanisms include Institutional Review Boards, Business Associates Agreement (BAA), and Data Use & Reciprocal Support Agreements. As each covered entity chooses the safeguards that best meet its individual needs, the types of protections applied may not be the same across all participants exchanging electronic health information. OCHIN requires that all data in transit between its facilities and third parties be encrypted at or above Triple-DES (3DES) for VPNs or TLS/SSL encryption for website interactions and that contractual assurances exist in the form of a BAA or protection under contractual language. OCHIN has found that, when scaling out its solutions to exchange data with an increasing number of entities, <u>trust</u> is based on professionalism rather than technology solutions. Exchange between Epic organizations is governed by Epic's Care Everywhere "rules of the road," while exchange on the eHealth Exchange is governed by the DURSA. As we investigate implementation of Direct Messaging, we have found Health Information Service Providers (HISPs) that will only connect with DirectTrust accredited organizations; however, this is leaving many providers disconnected from exchanges. <u>Technical</u> solutions are limited, and it is impossible for us to verify that partners are using best practices within their organization unless we are willing to pay for audits of the organizations on an ongoing basis, providing us with proof that they are in compliance.

3) What governance challenges are putting patient safety and/or privacy at risk, when health information exchange is occurring?

In good faith, there are existing laws that do make data sharing more challenging, including HIPAA and CFR 42 Part 2. However, many regulations were written (with some updates) prior to the technical ability to share data securely via electronic modes. The regulations need to be further updated and clarified as they relate to HIE. There will need to be more communication from state and federal agencies so that all organizations are using the same interpretation. Communication to users (clinical and patients) will need to include specialty boards (behavioral health, infectious disease, primary care, etc.), state pharmacy boards (regarding e-prescribing and sharing of medication dispensing records), and patient advocacy groups.

Some healthcare organizations are unwilling to share data for fear of losing market share and competitive advantage, to the detriment of the Triple Aim for improving healthcare. We find this especially troubling in our safety net organizations, which often do not have access to larger data sets. We favor "carrot-and-stick" policy changes, including alternative payment methodologies, which favor data exchange and knowledge transparency, and programs like Open Notes (www.myopennotes.org).

The difficulty of patient matching is particularly acute at OCHIN given the diversity of our patient population (less common names, more address discrepancies, and often unknown dates of birth). The potential for harm comes just as much from matching to the wrong patient as it does from *not* matching to a common patient and not having access to critical health data. Healthcare organizations – and patients – need to understand the implications of name spellings and the accuracy of demographic data. Patients whose date of birth (DOB) is unknown should be encouraged to select (and use consistently) a DOB other than 01/01/19x0 - a convention used widely enough that it degrades patient matching significantly. In the absence of a national patient identifier, patients could voluntarily choose one way to spell their name, select a set of identifiers (DOB, phone number, etc), fill in a standardized card to carry, and present the card at all medical encounters. Clinic workflows could include asking to review the card at registration. Efforts to create a standardized patient matching "voluntary card" could come from grass roots organizations if the political climate prevents state or federal programs from participating.

Example: Juan Carlos Fernandez (name changed for this example) is a recent immigrant from Mexico. He does not have his own housing, so he stays with various family members. When he was seen by a local Emergency Department, he was registered as "Juan Carlosfernandez" from Portland, Oregon (living at his sister's). In the ED, he had a mild adverse reaction to cephalexin antibiotic; the allergy was recorded in the hospital's Epic EHR. Months later, Juan Carlos was seen at a local FQHC using OCHIN's Epic EHR, and he was registered there as "Juan Fernandez" from Portland, Oregon (living at his new apartment). The physician at the FQHC queried Care Everywhere in Epic for the ED records, but the systems did not find a match. The patient did not relate the history of the allergic reaction, received cephalexin, and was hospitalized for two days after a more serious reaction.

4) What factors are limiting the exchange of health information?

As noted above, the lack of standards is a major limiting factor. In addition to technical standards and regulatory realignment (as discussed above), we note the continued differences between quality reporting metrics (Meaningful Use, Universal Data System required for FQHCs, NCQA Patient Centered Medical Home, Healthcare Effectiveness Data and Information Set, etc.). Although there has been improvement, the differences are still handicapping OCHIN by tripling work for these reports.

In addition, we are plagued by the lack of standardized concept unique identifiers (CUI) for clinical quality measures. The mix of CPT, LOINC, SNOMED, ICD-9, ICD-10, and other terminologies is crushing. In some cases, we have trouble finding an accurate but generalizable CUI, having instead to create an internal use code recognized only within the OCHIN data set.

Example: Patients or their medical records will indicate a history of a colonoscopy in 2011. The EHR, in the surgical/procedure history section, uses an import of CPT terms, including approximately 20 options for colonoscopy. There is no CPT code in the system for "colonoscopy NOS." OCHIN has created a fake CPT code (HX0060) labeled "colonoscopy," but the code does not match any similar code used outside of OCHIN. For reporting and data warehouse purposes, we map our HX0060 to a standard CPT code, which may be inaccurate (G0121 - "colorectal cancer screening; colonoscopy on individual not meeting criteria for individual at high risk").

OCHIN struggles, too, with the attribution of a Direct address to a specific provider. We have many physicians who each work in multiple settings for different healthcare organizations. How do we receive an inbound HIE message (C-CDA, etc.) and route it to the right place?

Example: Dr. Mettzenbaum works at the county TB clinic one day per week, but she also sees patients at the local, independent Community Health Clinic several days per week. She is the medical director for a separate nursing home, and she volunteers with the homeless mobile clinic monthly. Does she have four unique Direct addresses? What happens to her address (and data exchanges) if she stops working at one facility?

There are limited legal and liability protections in place for providers who share data to support efforts to assess quality and to improve patient safety. Some research studies have protections from data discoverability; however, many providers are hesitant to exchange population health information that shows their care to be "imperfect" for fear of lawsuits.

Lastly, OCHIN has delayed in contracting with a HISP for our Transitions of Care work because few HISPs have demonstrated:
   a) The technical ability to exchange messages beyond their connected organizations
   b) The ability to scale HIE volume beyond a regional level
   c) The flexibility to meet rapidly evolving regulatory and use-case requirements
   d) The financial viability of the company to survive the next three-to-five years;
   e) The ability to automate the synchronization of provider directory addresses between HISPs and from a HISP to the EHR further. (Synchronization of directories (provider addresses) is still largely a manual process.)

5) **What, if any, actions should be taken at the national level to help address the governance challenges that are inhibiting the exchange of health information across entities or to mitigate risks to patient safety and/or privacy when exchange is occurring? What role should ONC or other federal agencies play? What role should states play? What role should the private sector play?**

OCHIN favors a stronger federal program to incentivize HIE through a combination of published standards. States could have the option of following the standards (with financial rewards) or creating different state-level standards (with financial penalties). The Medicaid 90/10 funding program could be one source for creating incentives.

In many cases, the requirements for HIE are driven by regulatory reporting. The number of mandatory clinical quality measures and other reports across federal, state, and payers needs to be cut back, consolidated, and further aligned. OCHIN does not believe that the reporting wheel needs to be reinvented (or vary) in different jurisdictions. There should be, in alignment, a defined "basic set of essential health information" (as outlined in the ONC 10-year vision). As a country, we know what needs to be measured to improve the nation's healthcare system in line with the Triple Aim. Let's agree on a limited data set and focus there. This focus will also need to be accompanied by a standardized and greatly simplified set of CUIs to match the measures. ***We cannot continue to have reporting – and thus HIE requirements – defined differently by every state, county, and payer.***

We also believe that patient engagement is one of the unmet gaps in HIE. We applaud ONC in pursuing a vendor-neutral patient health record (PHR) that could consolidate data from any source, allow for patient annotation of the records, and allow the patient to transmit the record to any provider or facility. ONC can also facilitate dialogue about unfettered access to data (test results and notes), as well as help the national conversation around proxy use of PHRs for adolescents and adults.

We also encourage ONC to work with other federal and state agencies to clarify regulations (HIPAA, CFR 42 Part 2) around HIE, and perhaps, more importantly, to communicate where regulations do *not* limit HIE.

There is a significant gap in the amount of data currently available in EHRs and the ability to meaningfully use this information for research. As a clinical data research network in PCORnet, we have become acutely aware of the onerous requirements currently placed on researchers aggregating EHR data for research. Often, the same datasets must be recreated for every new study; there is limited guidance, standards, and processes that enable the creation of secondary datasets that can be used in multiple research studies. To help capitalize on this untapped research potential, we encourage ONC to create policies and protections to support and streamline secondary use of EHR data for research purposes.

Finally, organizations like OCHIN trying to achieve the Triple Aim through clinical improvement cycles and systems research need more access to the total costs of care, including access to claims data. As long as payers hold the data as proprietary, we cannot expect to improve value (quality/cost) as a learning healthcare system.

6) Would it be beneficial if ONC monitored the information exchange market to identify successes, challenges, and abuses? If so, what methods of monitoring would be effective and what actions should ONC take based upon findings from monitoring?

Yes. Shared learning would benefit OCHIN safety net partners. This could happen through continued work with Regional Extension Centers, national medical organizations (American Board of Family Medicine [ABFM], National Association of Community Health Centers [NACHC], etc.).

Potentially, ONC could develop a method of identifying organizations who are using HIE best practices—and those who are not. ONC could use a rating system for preferred partners, or a Consumer Reports-like method of rating. Alternately, ONC could encourage social media ratings— such as a *Yelp!* for HIE vendors.

It would be ideal to implement monitoring techniques that did not place further burden on providers and networks such as OCHIN.