Just Breathe It In

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Disclaimer

- All opinions are my own, and do not necessarily reflect the position of the National Library of Medicine, National Institutes of Health, or Department of Health and Human Services.
Standards -- how I got hooked

- As an intern at Boston City hospital it took a huge amount of time -- 4-6 hours -- to work up a new admission. Most of it gathering data.
- I dreamed of the time when all needed clinical data would be as immediately available as air – just “breathe it in”.
- I started building an EMR (1972-75) to realize that dream.
- Building the system was “easy”; getting the data in was difficult -- and remains the hard part today.
- We did get the EMR working in a 6,000 patient medicine clinic, published a paper in the *New England Journal of Medicine* showing the computer reminders helped.¹
- We used screen scraping, printer output capture, and smiley faces to capture data -- but it was tons of work, which became crushing as we expanded the system to all of the clinics.

Around 1980 I wrote the first version of a paper arguing that healthcare should imitate the grocery industry.

- They created bar code standards before they had bar code readers to read them.
- Developed the whole system in anticipation of its benefits.
- Got a huge pay off.
- Healthcare should do the same.

The paper got trashed by the reviewers from 10 journals and rejected.

- Shouldn’t standardize -- every patient is different
- There are no computers in healthcare to use the standards anyway.

Finally got published in AMA continuing ed. newsletter in 1983.¹

Had two meeting in the early 80’s: one in 1983 at AMSI (the first precursor of AMIA).

Then a panel with Ed Hammond, Don Simborg, Geo Wiederhold and 2 other luminaries at the SCAMC symposium in Washington, DC in 1984, specific proposal for an electronic test result message – focus on lab tests.

When asked why he robbed banks, Willie Sutton said because that is “where the money is.”

We started with labs because that is where the data is (probably 80% of it).
Two kinds of **depressing responses** from the attendees at the 1984 meeting:

- Start with **everything**. No point in doing lab tests until you can do all clinical data.
- Start really **small**. Don’t try to standardize the lab until you can standardize a electrolyte panel perfectly.

But one member of the audience was from **ASTM, an ANSI approved organization**, and he encouraged us to start a subcommittee to create this standard within ASTM (very big, esteemed consensus standards organization).

―Robin Sharma
So we started in ASTM committee E31.1 in early 1985.

In 1988 ASTM published first consensus standard for exchanging electronic clinical result information E1238-88.¹

(BTW, DICOM published first Imaging standard in 1985).

Followed shortly by a lab system to instrument standard E1394-91² which still runs in labs today.


HL7 message standard was alive but had not yet gotten rapid adoption

- In the 1985-87 time frame HL7 had not started developing observation messages standards.
- With encouragement from Don Simborg and huge help from Wes Rishel, a winter meeting at O’Hare, and cooperation from ASTM, we hammered out an approach to get the ASTM standard incorporated en bloc into HL7. It became part of HL7’s order entry (chapter 2), and all of its observation reporting (chapter 7). I chaired the ASTM and the HL7 O&O committee for many years, keeping both in sync.
- This is all detailed in a history of HL7 written by Rene Spronk. http://www.ringholm.com/docs/the_early_history_of_health_level_7_HL7.htm
- With HL7 adoption in hospitals, commercial labs burned through the industry like a wild fire.
- It was a miracle ingredient that made our Indianapolis Health Information Exchange possible. (Think there are now close to 2,000 HL7 interfaces and 4 billion results in the Indiana HIE.)
Health data standards across organizations and the remaining mega challenge

- HL7 worked quite well within hospitals. When we started the HIE in Indiana in 1994, we realized that we could not combine data from multiple hospitals without mapping the test codes from one hospital to a common HIE standard.
- We had to tweak many HL7 messages (½ to 2 person days of effort per stream), but that was nothing compared to 4-8 man-months(!!!) effort needed to map the 2-3 thousand lab tests from one lab to a common standard.
- The big challenge for inter-institutional communication lies with the observation codes not the messages.
In 1995 we started LOINC to blunt a criticism of HL7. Some people would say HL7 doesn’t work. HL7 worked fine, but what didn’t work were the idiosyncratic codes used by each hospital to define its observation codes.

The LOINC observation codes provide the sinews needed to pull together the same set of observations on one patient but stored across many different organizations.

Lots of progress. International adoption.
- More than 45,500 people in 173 countries.
- 12+ translations languages/dialects

Many collaborations...with:
- IEEE for instrument variables
- RADLEX and RSNA for structured radiology test names (and codes)
- American Nursing Association for nursing assessments
- CMS for its health assessments
- National Eye Institute for clinical and instrument Ophthalmology measures
- DICOM for cardiac Echo measurements
- And more

A universal code system for tests, measurements, and observations.
A word on Units of measure

For numeric data, we standardized units to make them fully computable.

- For numeric data – which EMRs carry in profusion – we also need standardized units of measure (UoM).
- UCUM\(^1\) (from Gunther Shadow) is what we need, and it has been adopted by IEEE, HL7, DICOM, ISO (ISO 11240) and Pharma’s International Counsel on Harmonization (IHC).
- UCUM is a syntax that permits automatic conversion between commensurate UoM.
- We also need a lightweight open-source UCUM validator and converter.
- We now have that -- JavaScript open source version courtesy of Lister Hill Center at NLM (it is available, but still being polished). The website provides a batch validator and a one off converter and validator. [https://lhncbc.github.io/ucum-lhc/](https://lhncbc.github.io/ucum-lhc/)

In Closing

- NLM has been a supporter and encourager of all of the standards needed for EMR since long before I worked there. Many thanks to the leadership that had the foresight to support such efforts.
- We still have lots of work to do and miles to go before we reach the “just breathe it in” stage of health care data. But we are getting closer.
- If policy makers would push a little harder on the use of standardized observation codes -- the rate-limiting step -- it could happen soon.