Testimony to the National Committee on Vital & Health Statistics Subcommittee on Standards

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Expressed goal of this hearing: Improve Processes for Standards

- What are major recent HIT standards development, selection, &/or implementation achievements?
  Describe enabling processes.
- What HIT standards, development, selection, &/or implementation challenges remain?
- What should model be for development, adoption, & implementation of HIT standards for nation as a whole?
- Who are the players & who should be involved?

1· What are major recent HIT standards development, selection, &/or implementation achievements?

- HITSP implementation specifications
- Structured product labels for approved drugs - disseminated via DailyMed, linked to RxNorm & other knowledge sources, e.g., ClinicalTrials.gov
- Promotion of International adoption of standard terminology:Formation of International Health Terminology Standards Development Organisation (IHTSDO) plus more coordination among ISO,CEN, HL7, IHTSDO, & CDISC
- Proactive expansion of LOINC to include genetic tests & newborn screening tests
- New version of Surgeon General's Family Health History tool, with standards, e.g., SNOMED CT, HL7, built in
- AHIC Working Group on Personalized health care standards matrix [tests (LOINC) that detect conditions (SNOMED CT)] for newborn screening.
- Important international standards published by ISO on the EHR and on privacy and security

1b. Describe HIT Standards Processes

Then – Bottom up

+ Well vetted
+ Experts committed
- Too many standards
- Slow to achieve global harmonization
- $s & Site(s) for Maintenance & Access
- Limited vision
+ Devil you know
- Idealism over pragmatism

Emerging – Top down

+ Actual standards can be set
+ Potential for globalization
+ Potential for Stable Funding & Maintenance/Access
- Needed standards don't get considered or move forward for political reasons (wrong cooks stirring the pot?)
+/- Sufficient vetting
- Unintended consequences
- Idealism over pragmatism

AMIA

2. What HIT standards, development, selection, &/or implementation challenges remain?*

- Decision Support
- Personalized Care
- Population Health Support
- Semantic interoperability, tying SNOMED CT to record structures
- Clinical knowledge models that reflect clinical best practice

- Selection challenge
  - Device terminology & identifiers

* But wait, there's more coming later.

3· What should the model be for development, adoption, & implementation of **HIT** standards for nation as a whole?

Process Model: Label data at source –

- LOINC on test kits
- Outputs from test devices labeled with LOINC
- RxNorm available with drug is approved & SPL is released

Rephrased 3. What Model is needed for development, adoption, & implementation of HIT & **HCT** standards for the nation as a whole?

NCVHS needs to develop an Outcomes Model that uses complementary HIT & HCT *(Health Communications Technology)* **Standards if we are to reach desired societal values**

- Health information & health communications are not the same. We need both.

Standards are explicit representations that reflect our view of the world &, hence, what we choose to recognize & value.

Values: Moral Attitudes & Habits

Standards inevitably lead our thinking toward certain measures.

The Link between Standards & Values

The Surgeon: *What possible difference does it make what my standards are?*

Elephant Man: *Because it is your standards we live by.*

- Paraphrased from "The Elephant Man"

An NCVHS Outcome Model for Standards Development is needed.

- And, a key consideration is currently ignored.

We focus far too disproportionately on standards for HIT (Information).

We ignore far too much needed standards for HCT (Communications).

A difference is a difference if it makes a difference.

- We need standards for both HIT & HCT.

  Ex: Advanced Directives for End-of-Life care.

  HIT End-of-Life Standards describe templates to accurately express information regarding personal choices.

  HCT End-of-Life Standards assure: 1) currency of directives & 2) that current directives are actually delivered to relevant caregivers in a timely manner.

  Like difference b/n quality measurement v. quality improvement.

Otherwise,

That which is measured drives out that which is important.

- Rene Dubos

What vision does America seek to achieve for its people?

What road will we follow?

- **Healthy people living in an altruistic society**
  - Social Determinates of Health ~50% of health status
    - Meaningful employment
    - Shelter
    - Education
    - Safe environment
  - Healthcare that is equitable, efficient, effective, patient & population-centered, timely, & safe

What are we achieving today?
Neither greater Health nor greater Altruism

- Rising unemployment
- Rising loss of homes
- Rising loss of insurance
- Rising numbers of poor children
- Rising health care costs with rising poor system performance in international comparisons
- Rising imbalance among key social goods
- Stock market yesterday at level when I chaired NCVHS over a decade ago.

What is required for America to achieve these values for its people?

Standards that create a better balance among competing social goods

- Altruism
- Freedom
- Healthy Individuals
- Healthy Communities
- Personal privacy
- Personal autonomy
- Useful Knowledge

How might America achieve this?
New Model NCVHS-approved HIT & HCT Standards

- Value-driven Care deserves Value-drive Standards
  - As defined by the patient, e.g., FREE access to personal & altruistic options
  - As defined by the health professional based upon relevant evolving knowledge (NRC Computational Technology for Effective Health Care – 2009)
  - As defined by equitable, safe, efficient, timely, patient-centered, & effective standards (IOM Chasm – 2000)

- HIT & HCT Standards compatible with care that is:
  - Evidence-based
  - Delivered by a team
  - Patient-centered
  - Continuously improving quality
  - Utilizes Informatics (IOM Education Summit – 2003)

What is required for America to achieve these values for its people?

NCVHS needs a Model to derive relevant HIT & HCT Standards to enhance Equity, Patient-centeredness, Timeliness to match growing focus on Effectiveness, Efficiency, & Safety

Ex., Underinsurance & Lack of Insurance

A New Model is Needed

Today there is scant support for Americans to choose b/n Altruistic v. Self(ish) Goals

Today HIPAA limits access to Useful Knowledge, e.g. legitimate Biomedical & Health Research*:

Examples:

1) Today, no simple consent generic procedure to allow citizens to share personal health data for legitimate scientific research

2) Increasingly expensive unfunded mandates keep being enacted without clear health benefits & that are likely to further hurt biomedical & health research supported through public funds

Ex. New regulations on de-identified data & what will fall under minimum necessary data

3) Few standards explicitly that support solely community benefit

*AAMC (earlier), AAHC (2009), IOM (2009) Reports

2. What HICT standards, development, selection, &/or implementation challenges remain?

- Decision Support
- Personalized Care
- Population Health Support
- Semantic interoperability, tying SNOMED CT to record structures
- Clinical knowledge models that reflect clinical best practice
- Selection challenges
  - For each of the above

3· What should the model be for the development, adoption, and implementation of HIT & HCT standards for the nation as a whole?

The model should be an OUTCOME MODEL that reflects important NAS/IOM/NRC/NAE/AMIA/AAHC/AAMC/International Groups with other key reports relating to Quality, Safety, Public Health, Privacy, Health Information & Communication Technology and its Use; Computer-based Health Records, Rural Health, & Research

Then, the processes for developing relevant HIT & HCT standards may better reflect core American values & creating global markets for products that adopt them.

Question for NCVHS

Do you need a new working group aka the NHII Working Group to "take on" this new robust HICT Standards model?

4. Who are the players & who should be involved?

Whoever is hungry plus whoever else shows up.

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* the AMIA staff, & AMIAs nearly 4000 other informaticians stand ready to help you.

Thank you again for the invitation.

My presentation will be posted at http://www.amia.org

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