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2020-2025 Federal Health IT Strategic Plan Comments

In general I support most of the concepts and general direction of this plan. I do however believe that the core problem in health IT is not the lack of available APIs for acquiring health data, this issue is being addressed by the private sector health IT suppliers and need only be implemented by health care providers. I also do not see that a focus on HIE to HIE interoperability for the less than 5% of the population who can benefit from this work is needed when SHIEC and other non-government entities are working to deploy pragmatic solutions not based on an archaic set of IHE profiles.

Data from my 30+ years of experience in health IT tells me there are three (3) areas should receive focus as opposed to those above. They are:

1. NCQA licensing of eCQM and dQM measures is a confusing mess with the NCQA expressing different opinions regarding the inclusion of their measures in commercial products which are sold and deployed in direct patient care setting. I believe that HHS/ONC should license a broad set of measures, upon which federal regulations can be anchored and that these measure sets should be packaged for easy use and at no charge to the healthcare provider, just as HHS did many years ago with SNOMED, enabling use of this terminology in a wide variety of health IT systems advancing interoperability and standardized nomenclature.
2. Patient privacy. While I do not agree with the approach or position of Epic, I do believe that there is a need for more work/regulation in the area of patient privacy and consent. No data should be sold or released to non-HIPAA covered entities, deidentified or not, without the express consent of the patient or authorized family member.
3. Data quality. As much as 84% of all healthcare IT data acquired and stored by EMR systems or exchanged via interoperability is of poor or low quality, rendering the data useless, confusing and potentially dangerous to the patient. The remainder of my comments will deal directly with this issue and the impact of this issue on other aspects of this strategic plan.

# 84% of health IT data is poor or low quality, putting patients at risk

**Goal 3:** Build a Secure, Data-Driven Ecosystem to Accelerate Research and Innovation

**Objective 3a:** Advance individual and population-level transfer of health data

**Strategy #1** – Improve harmonization of data elements and standards by creating a common vocabulary set to improve the consistency, integrity and quality of data and to enable data to be effectively shared between systems using API’s.

**This is probably the most important strategy in this whole document, for without it many of the other goals and objectives cannot be achieved, or will be greatly reduced.** Those include:

**Goal 1: Objective 1a: Strategy 1: Enable individuals to access their health information** … Comment: information that is not structured, standardized, normalized and harmonized is not very useful in mobile apps, portals, AI or machine learning tools. In addition, much of the data needed is only found in text based documentation, the structure data sets must be expanded to be useful.

**Goal 1: Objective 1a: Strategy 2: Promote greater portability of health information** … Comment: for health information to be effective when portable it must have a greater scope (less text) and be more structured, standardized, normalized and harmonized.

**Goal 1: Objective 1b: Strategy #1: Promote healthy behaviors and self-management through patient facing apps** … Comments: Another example where new vocabularies and data sets are needed to facilitate the effective and meaningful exchange of health data between patients and care providers.

**Goal 1: Objective 1c: Strategy #1: Strengthen communities’ health IT infrastructure …** Comment: Much of the data exchanged today is unusable since it is often only found in text, increasing the volume of poor quality data does not achieve the goal and in fact retards progress.

**Goal 1: Objective 1c: Strategy #3: Capture and integrate social determinants of health data** … Comment: New vocabulary and terminologies are needed to support this strategy.

**Goal 2: Objective 2a: Strategy #1: Optimize care delivery by applying advanced capabilities like machine learning** … Comments: Poor data quality and limited sets of structured data are again the biggest barrier to the wider development and use of machine learning in health care. Much of the data needed such as stroke index or gestational age is only found in textual data which is highly unreliable. Increasing the number and scope of clinical vocabularies and reducing optionality of responses is required to make significant advances on this objective.

**Goal 2: Objective 2a: Strategy #7: Promote interoperability and data sharing through widely-accepted standards to ensure health information is freely available…** Comments: Again, increasing the sources of poor quality unstructured data does little to accomplish the actual use case for interoperability and has been shown to increase provider burn-out. The key is to improved data quality first then promote the exchange.

**Goal 3: Objective 3a: Strategy #2: Bolster secure access to large datasets** … Comments: Large data sets are of little relative value if the data quality (structure, standardization, normalization and harmonization) is poor.

**Goal 4: Objective 4b: Strategy #1: Address Information blocking** … Comments: Poor quality data which is not harmonized between providers may be worse than outright information blocking, if the information exchanged is of poor quality, using different standards, structures or terminologies. A provider can think they are seeing and understanding the data when they are not.

**Goal 4: Objective 4d: Strategy #3: Increase patient understanding** … Comments: Patients and their care givers have even less capability to understand the data which is not standardized, normalized and deduplicated. Understanding that the duplicative nomenclature or that medications may have trade names, generic names or both. The strategy for increasing patient understanding MUST include data standardization, normalization and deduplication in addition to FHIR APIs and other transport technology.

# Summary

The poor data quality of current health IT systems is the biggest problem facing health IT today. This problem of data quality is due to a lack standardization (or maybe too many standards with too much optionality) and the very limited set of structured data elements and multiplicity of terminologies is currently the biggest barrier to effective interoperability, analytics, AI, machine learning, provider burn-out and patient frustration.