Sequoia Project – Data Usability Workgroup
Proposed Data Usability Characteristics – DRAFT – 16 November 2020

At the first meeting of the Sequoia Project/Data Usability Workgroup we established that data usability is as viewed from the perspective of the end use/end user (e.g., clinician) – and is an expectation that we plan to fulfill. So what are the key qualities (characteristics) of data that promote usability (use, usefulness)?

- Is the data true (accurate, authentic) and trustworthy (assured)?
- Is the data timely, current?
- Is the data relevant?
- Is the data digestible, comprehend-able?
- Is the data action-able in support of real-time care delivery and/or a specific end use?
- What is immediately *known* (knowable, evident) regarding data content?

To avoid concerns regarding burden, let's assume that vital data qualities are present and managed by underlying system and data exchange infrastructure but not necessarily visible in the initial "top view" – i.e., evidence of these qualities might be accessed via a "drill-down view" capability.

Here's how our end use/end user will gain a perspective on, and fulfill his/her expectation of, data quality and thus data usability. (The following is derived from recent work of the HL7 EHR Work Group, Reducing Clinician Burden Project.)

Chain of Trust

Data is carried via a verifiable chain of trust from **source to end use**:
- Starting as captured at the **source** (point of origination), then
- Retained in the source EHR/HIT system, then
- Transmitted from the source system, then
- Received and retained by the receiving EHR/HIT system, then
- Made available to each ultimate **end use and user** (point of access/use).

Vital Data Qualities

Vital Data Qualities	Capabilities and safeguards must ensure datasets and data elements...
Known **and verified (verifiable) as to identity**: • Subject: patient • Provider: individual and organization • Systems, devices and software	Are associated with the correct identity and subject (of care/treatment)
Known **and tied to actions taken: who did what, when, where and why** • Actions are taken to support individual health, to provide healthcare... • Data resulting from actions taken includes facts, findings, observations...	Show a clear relationship/binding of datasets/data elements with actions taken – who took what action, when, where and why
Known **to be oriented in time: date/time of occurrence, chronology, sequence** • What has happened: past, retrospective • What is now in progress: present, concurrent • What is anticipated, planned: future, prospective	Show time orientation and chronology/ sequence
Known **to retain clinical context and maintain vital inter-relationships** among/between (as applicable): • Problems, diagnoses, complaints, symptoms, encounters, history and physical findings, allergies, medications, vaccinations, assessments, goals/objectives, clinical decisions, orders, results,	Show clear inter-relationships/binding between datasets/data elements and their clinical context (as noted in the left-hand column)

Vital Data Qualities	Capabilities and safeguards must ensure datasets and data elements...
diagnostic procedures, interventions, observations, treatments/therapies, referrals, consults, outcomes, protocols, care plans and status...	
Known **as to source and provenance ("source of truth")**, with traceability to point of origination: human, device, software	Show dataset/data element provenance with traceability to source/point of origination
Known **as to accountable human authorship** (if applicable) with role and credentials	Show dataset/data element authorship with role and credentials, as applicable
Known **to be verified/attested (or not)** with evidence of verification/attestation, verifier(s)/ attester(s), date(s)/time(s) and method(s) • Human verification of data sourced by automated device • Preceptor verification of data sourced by student • Attestation of facts/findings to substantiate claim for payment	Show evidence of dataset/element verification, as applicable
Known **to be updated (or not)** with evidence of prior state(s), effective date(s)/time(s) • Non-destructive update	Show evidence of dataset/data element update, prior state(s), effective date(s)/time(s), as applicable
Known **to be unaltered** (maintaining fidelity to original/source content) or ***Known*** **to be altered/transformed** from source content/representation to another • From one coding/classification system to another, or • From one human language to another	Show evidence of dataset/data element non-alteration or alteration, as applicable
***Known*, if altered/transformed, to carry original content/representation alongside (or not)**	Carry original dataset/data element content (or not), as applicable
Known **to be complete** or ***Known*** **to be incomplete, partial or pending** or ***Known*** **to be a snippet/fragment** with other essential details elsewhere	Show notation of dataset/data element completeness (or not), as applicable
Known **to be associable and congruent with like data**, having same/similar context • Correlate-able, trend-able	Have the same/similar context so as to be comparable, even/especially if sourced by separate EHR/HIT systems
Known **to be consistent – in terms of data definition – with corresponding data**: • Common element name(s), common data type(s), common range (including normal or reference range), common input/display/storage format, common unit(s) and scale of measure, common vocabulary, common codes and value sets	Have consistent data naming and definition, even/especially if sourced by separate EHR/HIT systems
Known **to be sourced as structured (coded) content or not**	Show data source as structured content or not
***Known*, if coded, to include:** • Coding convention – vocabulary/terminology set or value set – and version	Show coding convention and version, if applicable
Known **as to method and purpose of data capture**	Show method and purpose of capture, if applicable
Known **as to intended purpose of data use**	Show intended purpose of use, if applicable
Known **if captured from external sources**	Show external data source, if applicable
Known **as to how external data is integrated with or maintained separately from** health data/records in local EHR/HIT system	Show data integration or segregation, as applicable

Immediate Context

It is essential that *immediate context* be bound to and managed alongside each dataset and data element. For example, blood pressure should include the following elements of *immediate context*, including provenance:

Who (actor)	Patient or subject of care
	Performer, who measured blood pressure
	Author of health record entry (who may be different than performer)
	Provider: individual practice or organization
What (action taken)	Systolic, diastolic and/or mean measurement
When	Occurred at: date/time/duration
	Recorded at: date/time
Where	Body location, sampling site
	Physical location – e.g., exam room, bedside
	Recorded at: network address and/or device ID
Why	Rationale for, or purpose of, measurement
How	Method – e.g., inflatable cuff with auscultation by stethoscope
Under what circumstance(s) or condition(s)	At rest, pre/post exercise or other condition

To be complete and to establish trust (assurance) and truth (authenticity, accuracy), each element of health information must be carried together and tightly coupled with its *immediate context*.

Extended Context

Extended context shows key relationships beyond the immediate measurement (for example, extending the context of our blood pressure example):

Extended Context	Blood pressure measurement occurring as:
a) Basic vital signs panel	Part of a vital signs panel (e.g., heart rate, respiratory rate, body temperature, pulse oximeter) as might be captured from the same patient, by the same performer, at the same date/time
b) Inpatient vital sign monitoring	Part of a vital signs panel (as detailed in "a" above), as might be performed hourly in an inpatient setting
c) Outpatient history and physical assessment	Part of a vital signs panel (as detailed in "a" above), performed in an outpatient clinic, in conjunction with a history and physical assessment
d) Weekly monitoring – to rule in/out hypertension	Weekly follow up visits measuring vital signs (as follow up to "c" above) to determine if patient has hypertension (high blood pressure), performed in an outpatient clinic for four successive weeks
e) Weekly monitoring – post hypertension diagnosis	Weekly follow up visits measuring vital signs to assess effectiveness, dosage levels and possible side effects of medication prescribed after patient was diagnosed with hypertension (as follow up to elevated BP levels detected from monitoring described in "d" above)

To be complete and to establish trust (assurance) and truth (authenticity, accuracy), each element of health information must be carried together and tightly coupled with its *extended context*.

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