

Two Key EHR-Related Catalysts to Support Patient Engagement and Accelerated Health System Transformation:

Effective View, Download and Transmit Capabilities and Actionable Recorded Patient Preferences

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Overview

The HIT Standards Committee Patient Engagement Power Team held a series of intense full group and sub workgroup calls over a compressed three-week period. From those collective group discussions emerged two primary catalysts that the collective group believes can act as key enablers to support patient engagement and its impact on accelerating health system transformation:

1. Effective EHR View, Download and Transmit (VDT) Capabilities
2. Actionable EHR Patient Preferences Fields

Specific elements highlighted below and their associated recommendations were accumulated from the Patient Engagement Power Team conference calls described above, as well as other related venues: S&I Framework F2F meeting discussions, MU Policy Workgroup F2F and Full Policy Committee F2F meeting discussions over roughly the past month.

Discussions on the staging of these capabilities for Meaningful Use resulted in recommendations as to whether a particular item is desired to be designated Stage 2 (Core or Menu) or Stage 3. The team understands the current boundaries of the NPRM process and has made formal comments that are a 'logical outgrowth' from the NPRM. However, The Power Team members reiterated several times during the discussions that it is important to provide a full set of recommendations so that the consumer/patient engagement enablement 'big picture' can be communicated to the industry, without it being limited by speculating as to what may or may not be accepted and incorporated into the final Stage 2 rules.

The thoughtful input brought to the table by the Power Team participants and the subsequent rich discussions demonstrates their enthusiasm and commitment to patient engagement.

Effective EHR View, Download and Transmit (VDT) Capabilities

Effective view, download and transmit EHR capabilities are foundational not only for patient engagement but also to support the transformational shift to a learning health and health care system. Each function (view, download and transmit) plays a complementary role in addressing the required use scenarios.

Three core principals emerged from the Power Team discussions in support of this premise:

- Designated Proxy - The patient has the right to designate a proxy (or proxies) indicating that interactions traditionally intended for the patient are handled by the designee(s) with and/or instead of the patient herself. Thus all comments related to patients below also apply to their designee(s), if any.
- CC:ME - Any health information that is shared with providers and/or with the patient as an information exchange, discussion item or handout should be made available electronically with discrete computable fields and/or human readable format, based on patient preferences.
- Incorporation of Patient Generated Data – Much of the information required to inform care decisions is gathered through a variety of inefficient and ad-hoc methods which can be significantly streamlined for efficiency and effectiveness. Standards developed for surveys of patient experience of care can be used in other applications.

As a key member of the care team, the patient or their designee(s), like all other members of the team, must be able to BOTH receive AND provide contextual, actionable information to improve the individual and team decision-making required for a successful team-based outcome. Full value is realized from health information *exchange*, not just one-way provider to patient health information *hand-off*.

View & Download Capabilities

The view and download functions are associated with two main scenarios:

1. At some point after a care event, a patient collects existing records from their provider(s) portal to print, pass along to their other providers/caregivers, and/or to aggregate for use in a PHR or other tool. The consumer paradigm that this follows is on-line banking where the user selects date ranges, data types, etc., as well as output formats for both human readable (PDF, text) and discrete to be computable (for banking it is Quicken, XLS but for health care it would be C-CDA). Data must remain in its raw clinical form so that if it is passed to a downstream physician so they can use it accordingly (this discussion point was reiterated at the most recent Policy Committee meeting).

Recommendation: Support in Stage 2 – Core. Rationale: Logical NPRM Extension by clarifying the specifics on how this would be accomplished.

2. At the point of care, the provider may want to invoke an HL7 “InfoButton” capability that creates patient-contextual educational information, at which time the information is printed and handed to them and/or sent to them electronically based on their

preference. The “InfoButton” related process could be enhanced to also support the distribution of the clinical summary data (see ‘Transmit’ section below) at the same time, to provide a more complete view of the information and enable a key ‘teachable moment’.

Recommendation: Support in Stage 2 – Core. Rationale: Logical NPRM Extension by clarifying the specifics on how this would be accomplished.

Transmit Capability

The Transmit function is associated with three main scenarios:

1. Health information is selected on-demand and sent to one or more patient-designated recipients (e.g. PHR, PCP, medical home, long-term care facility, ACO, condition/disease registry, clinical research, etc.) via a ‘Direct’ address or other approved standards-based mechanism. Processes to support this would need to be set-up by patient self-service in the portal or within the registration process of the admission/encounter.

Recommendation: Support in Stage 2 – Core. Rationale: Logical NPRM Extension by clarifying the specifics on how this would be accomplished.

2. Based on a standing preference (patient order) that any information or action related to the patient (care summary, Rx, education materials, discharge summary, etc.) is sent to the patient (CC:ME) and/or to one or more patient designated recipients (e.g. PHR, PCP, long term care, medical home, ACO, condition/disease registry, clinical research, etc.) via a Direct address or other approved standards based mechanism. Setting up and executing this type of automated information exchange without the required intervention of either provider or patient time/resources addresses one of the core requirements of health care system transformation, which is to drive out cost through efficiency.

Recommendation: Support in Stage 2 – Core. Rationale: Logical NPRM Extension by clarifying the specifics on how this would be accomplished.

3. Patient generated (self-entered and/or device) discrete data is exchanged before, at the point of care (physical or virtual) and after the care interaction, according to care plan and evidence-based medicine tasks. Examples include patient-sourced med list for med reconciliation; biometrics such as weight, blood pressure, glucose, assessment surveys (such as health risk assessments, depression, ADHD); observations of daily living (mood, pain, exercise); updated family history; allergies; medication tolerance, etc. This patient sourced data should be acquired through forms on the patient web portal and/or (patient's choice) through the transmission from a patient controlled system such as a PHR. Either way it would be transmitted/saved in the C-CDA format (may require new fields and templates).

Recommendation: Minimum current medication list (for medication reconciliation) for Stage 2 – Menu. Rationale: Logical NPRM Extension by clarifying the specifics of how this would be accomplished. The recommendation for Stage 2 Menu reflects the Power

Team's understanding of the complexity in incorporating externally sourced discrete data into the EHR. However, the Patient Engagement Power Team would also like to send a strong signal to the market that a wide variety of patient generated data processes will need to be required in Stage 3.

Processes to support the above three scenarios will need to be set-up for patient self-service in the portal or within the in-person registration process of the admission/encounter (see preferences section below for details).

Key VDT Attributes To Maximize Health System Efficiency and Effectiveness

In order to communicate more specifics nuances to the full Standards Committee, the group identified the following key attributes that need to be taken into account for VDT:

- Data recipient usability - Raw clinical data is translated to patient health literacy level at the patient interface point so that the clinical context is not lost. For example, if a paper copy is handed to the patient, the translation is done when this happens (at the point of care or at discharge). If the raw data is sent to the patient controlled system such as a PHR and they want to see the info by itself or aggregated with other data, the translation is done there, as part of the PHR viewer or related application.
- Avoid data fidelity loss - Data must be transferred at the level it is captured and tracked - if captured within the EHR at a discrete field level then data should move at the same level, and the data not allowed to be rolled into text/document 'blobs' that make the data un-computable and significantly lowers the value of the health information exchange.
- Information accessibility: 2 business days (new recommendation from MU WG) is too long - this should be real time for what is available and any lagging information (such as lab tests, pathology, etc.) would be available as it comes in (ideally there would be an indicator that results are pending so all stakeholders know the status of an open item). The clinical summary, discharge summary and any other information need to be made immediately available so that the patient, their informal caregiver, next day PCP/specialist appointment, etc., completely understand what happened in the previous care process and begin to execute the self-care and/or referral care plan/instructions correctly right away to maximize the safety, quality and cost effectiveness of the overall clinical outcome.
- Introduction of "health" to health care delivery - Diet and exercise are key to planning for and measuring outcomes related to better health (See the following 'preferences' section for physical activity and nutrition details).

Actionable EHR Recorded Patient Preferences Fields And Potential Supporting Standards For Them

Overview

Transformation of the current health delivery system requires patients and physician/care teams to interact in much different ways than they have in the past. These new data/information/knowledge information-enhanced interactions support better patient contextual care, patient engagement, joint decision-making, and joint accountability required for a safer, higher quality, lower cost health and health care system.

It is critical that a robust baseline of patient preferences are incorporated into Meaningful Use Stage 2 to form the foundation for creating more effective and patient-accountable care plans, interventions and outcomes to leverage in Stage 3. At the same time it is very important to send a strong signal to the market as to what Stage 3 likely will require so that HIT product innovation can begin now and not wait three or more years to get started.

Existing Related Elements in MU Stage 2 For Discussion Context

The following patient preferences related elements exist in the current Stage 2 and Certification NPRMs:

1. **Communication medium**
 - a. NPRM is seeking comment (see below)
2. **Advance Directives** (indicator whether one exists or not)
 - a. Needs to be extended (see below)
3. **Preferred language** (under demographics)
 - a. May need to be extended (see below)
4. **View, download and Transmit an electronic copy of a patient's information**
 - a. VDT needs to be supported by patient preferences (see below)

Proposed New Patient Preference Elements

1. **Designated Proxy or Proxies**
 - a. Concept: **Formalize patient preference to have help in decision-making and information sharing** (verbal, paper, secure messaging): this can be family, friends, caregivers, etc.
 - b. **Stage 2 Core:** Fields - List of names and relationship to patient, contact information (phone1, phone 2, email, Direct address, etc.), whether for decision-making, information sharing or both
 - i. May be able to partially handle using one or more of the following sections of C-CDA: advance directives, information recipient, supporting person, custodian, participant, informant and consent (not privacy related).

2. Standing 'Order' By Patient For Information Distribution(s)

- a. Concept: ***Put in place an efficient, automatic, cost effective electronic information transfer process*** for both: 1) discharge or encounter completion, an auto-distribution of relevant info (clinical summary, care plan, instructions, images [actual files and/or pointers] done to the recipients identified, 2) forward a copy of ALL info that the provider sends to any other entities (referrals, researchers, etc.)
- b. Supports MU Stage 2 to be more effective – Applies to:
 - i. Electronic 'transmit' portion of the view, download and transmit
 - ii. Patient reminders
 - iii. Patient-specific educational materials
- c. **Stage 2 Core:** Fields - Recipient name (likely an entity name, entity type (e.g. person, PCP, other provider, PHR, medical home, long-term care facility, ACO, disease/condition registry, other), contact name and info (phone, email)
 - i. Could potentially be additive to the list above or separate
 - ii. May be able to partially handle using one or more of the following sections of C-CDA: advance directives, information recipient, supporting person, custodian, participant, informant and consent (not privacy related)
- d. Two approaches on how this might work were discussed: 1) it lists only one person/entity (e.g. patient-controlled PHR) where the copies to others are forwarded from to reduce complexity for EHR vendors and providers), and 2) have the capability for a reasonable number of electronic copies (e.g. 5 or 6) to be distributed per the patient preference.

3. Quality of Life Statement/Goals

- a. Context: ***Create a summary of a patient's goals and desired quality of life.*** The foundation of all care-related decision-making by every member of the care team should be within the context of the patient's overall quality of life goal(s); otherwise the outcomes are not correctly measured against this ultimate benchmark.
- b. **Stage 2 Core:** Fields
 - i. Option #1 – New Fields (text)
 1. Long term (on-going, foreseeable future): e.g. "Ability to play on the floor with my grand kids, walk with my wife and/or dog, not be embarrassed to go shirtless, take no or very few prescriptions, continue to intellectually be able to be productive at a job that I am passionate about."
 2. Short term (less than a year): "Look good in a tux for my daughter's October wedding. Lose enough weight to not be in the obese BMI category."
 - ii. Option #2
 1. Create new category within 'Plan of Care' C-CDA; alternatively could also be general status section (allows text string values) of C-CDA
- c. **Stage 3:** Fields – Include quantifiable dimensions based on research/existing standards that support rich on-going health and care plan interactions.

4. Advance Directives Extension

- a. Context: ***It is not good enough to know that an Advance Directive exists – This information needs to be actionable by making it actually available to guide care decisions.*** In fact, knowing that there is one but not having access to it could cause harm while the care team stops (because they have been informed that one exists and conservatively take the stance that a reasonable effort must be made to get the document), thus the family or proxy hunts for it while losing precious time before proceeding with a plan of care.
- b. **Stage 2 Core:** Fields
 - i. Identify location - Need to add the identification where the current active AD exists (could be a web link), contact info (name, entity, phone number, email address) for location.
 - 1. Attach copy of advance directive document(s)
 - a. Have copy of document(s) attached if the location referenced is this EHR system.
 - ii. CPR & intubation (C-CDA / SNOMED CT), per physician input as to highlighting the most critical decision elements within full list of discrete fields.
- c. **Stage 3:** Fields
 - i. All supported C-CDA fields related to Advance Directives and associated documents
 - ii. Versioning
 - 1. May need to have snapshots of associated specific ADs with specific care so that historically care actions are in the context of a specific AD.

5. Communication Medium

- a. Context: ***'NPRM is seeking comment' - The document states that 'it may be better integrated in other areas and not as a standalone criteria'***
 - i. ***The CE team disagrees*** – There needs to be a standalone section to be used as a default because there are communications that are not part of MU, e.g. marketing/newsletter communications, lab results where the preference is phone and it is ok to leave a message (individual communication programs etc. areas can override these defaults).
- b. **Stage 2 Core:** fields
 - i. List of communications items (appt. reminders, other reminders, lab results, Rx Refills, newsletters, etc.), channel (phone1/number1, phone2/number2, email1, email2, text message/number, secure messaging).
 - ii. Standard: new or could use the existing C-CDA General Status section (allows text string values).
- c. Note: Providers are concerned that if you list an email address and what they need to communicate is urgent; they want to reserve the right to override this (this is a very reasonable request and thus makes sense to communicate this notation to consumer/patients).

6. Preferred Language (Extension)

- a. Context: **Communication effectiveness requires knowing that in particular, English is a second language** (or that it is not) so that interpreters can be made available; communication language can take this into account in written and eventually electronic information sharing.
- b. **Stage 2 Menu:** Field - May want to consider including 'second language';
 - i. Standard: Language Communication section in C-CDA

7. Religious / Cultural

- a. Context: **Inform care/care plans to be in the context of preferred practices**, e.g. request to only assign female nurses to a Muslim woman.
- b. **Stage 2 Menu:** Fields – Exist within S&I process and data element dictionary
 - i. Alternatively could use the existing C-CDA General status section (allows text string values)
- c. **Stage 3:** build upon stage 2 with more discrete cultural-related fields

8. Nutrition

- Context: **Inform care/care plans with preference for vegan, vegetarian, no milk, etc.** The baseline preferences inform the rapidly adopted “Nutrition Care Process Model (NCPM)” by clinical dietitians. These fields should be acquired through forms on the patient web portal and/or in Stage 3 (patient's choice) through the transmission from a patient controlled system such as a PHR.
 - a. **Stage 2 Menu:** fields – Proposed fields exist within the S&I process and data element dictionary
 - i. Alternative would be leverage existing social history/nutrition C-CDA/SNOMED CT
 - b. **Stage 3:** Build upon stage 2 with the full set preference-related discrete fields; this includes nutrition activity (NCPM) compared against the preference(s) captured.

9. Physical Activity

- a. Context: **inform care/care plan with preferred level and type of physical activity, e.g. moderate three times a week for 40 minutes, prefer walking outside/treadmill, weights once a week; any restrictions that need to be accounted for.** These fields should be acquired through forms on the patient web portal and/or in Stage 3 (patient's choice) through the transmission from a patient controlled system such as a PHR.
- b. **Stage 2 Core:** Fields – Proposed fields within S&I process and associated data element dictionary.
 - i. #1: Number of days you exercise per week
 - ii. #2: How many minutes per day do you exercise where intensity is at least at a moderate level
 - iii. #3: Exercise Vital Sign (EVS) is calculated by minutes of exercise/week average – used currently in Kaiser EHR – see nutrition and exercise materials distributed at the first full team meeting
 - iv. #4: Long-term weight bearing restriction (functional status, C-CDA), could also use the existing C-CDA General status section (allows text string values)

- v. May be able to use existing standards for #1-#3 that could be coded in the social history/exercise portion of C-CDA/ SNOMED CT
- c. **Stage 3:** Build upon stage 2 with full set of discrete fields based on research; add additional fields for other functional status elements that are not such as 'preferences' but elements to be taken into consideration.