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Farzad Mostashari, M.D.

Office of the National Coordinator for Health Information Technology

Patriots Plaza III

355 E Street, SW

Washington, DC 20201

Re: Meaningful Use Stage 3, HIT Policy Committee Request for Comment (HHS-OS-2012-0007)

Dear Dr. Mostashari:

On behalf of the Society for Participatory Medicine, we are writing to applaud the announced goal of the HIT Policy Committee in using the occasion of Meaningful Use Stage 3 regulation development as an opportunity “to begin to transition from a setting-specific focus to a collaborative, patient- and family-centric approach.” We endorse the proposals that further this goal, and offer some focused recommendations intended to ensure that the final regulations are in fact designed to help achieve this goal.

The Society for Participatory Medicine has individual and institutional members nationwide comprising patients, non-professional caregivers, and clinicians. It was founded to study and promote participatory medicine, which is centered around networked patients shifting from being mere passengers to responsible drivers of their health, and providers who encourage and value them as full partners. For further background on the Society and its tenets, we invite you to peruse the Society’s website (<http://participatorymedicine.org>), its online journal, The Journal of Participatory Medicine (<http://jopm.org>) and its blog, e-patients.net (<http://e-patients.net>).

Our specific comments, keyed to the numbering of the proposals, follows:

SGRP

- I05 – Patient input to reconciliation of problems

This is an example of the opportunity presented for patients to help maintain data integrity of electronic health record (EHR) data. Other examples are found in SGRP I06 and I07 and 204D. We feel that patients should be involved in amending, reconciling, and correcting errors in their medical records. Making this possible will require EHRs that support patient assistance, patient portals or other

mechanisms for patients to do this online, and workflow tools for both providers and patients. We propose that ONC establish additional working groups or technical expert panels to study these issues and establish relevant standards.

- I 12 - Advance Directive

There should be a standardized way to link from the EHR directly to the patient's medical home EHR or PHR where the advance directive may be located.

- I 13 - External Decision Support based on patient specifics

Patients should have independent access to the same decision support resources as providers, as well as view log of provider overrides and reasons for overriding recommendations (to the extent they are available).

- I 14 - EHR will need to consume structured lab results

This requirement should apply explicitly to external results (tests ordered elsewhere) as well as those ordered by the provider, and those results must be part of the record that the patient can view, download, and transmit.

- I 18 - Images accessible in EHR made core objective

This requirement should be considered fulfilled if there is access to streaming images in order to avoid the requirement to store multiple copies of the same images.

- I 19 - Record Family History

This requirement should be considered satisfied through a standard link to patient's medical home or PHR. ONC should also consider recommending a standardized format for storing family history information.

- I 21 - Provide structured lab results to ambulatory providers

These results should be provided to the patient as well, simultaneously, and providers' review of results should be tracked and made auditable.

- 204A - VDT via Automate Blue Button Initiative

The 4 day and 36 hour delays to patient access to EHR data should be eliminated, with the understanding that the record may not yet be complete. Access to imaging should be added to ABBI.

Also, for providers to review and accept data into their EHR there must be machine-readable metatags containing time stamps and data provenance information.

- 204B - EHR to accept external input from patients

EHR should also be required to accept input from external providers and from devices.

- 204D - Enable patients to amend, correct EHR online

There is no measure proposed; to make it consistent with similar criteria, perhaps the requirement should be that such requests are processed for at least 10% of patients in no more than 36 hours, or immediately if then an inpatient. See also response to SGRP 105 above.

- 205 – Clinical Summary

In order to engage patients, the after-visit summary should contain (at the very least):

1. Medication changes (new, changed, and discontinued)
2. New problems addressed
3. Goals for patient and other care plans
4. Links to information

- 207 – Electronic Messaging

We recommend a formal review be performed (e.g., by HITPC) to determine what an appropriate threshold would be based on sites that have been using secure messaging, but this must be adjusted for patient population.

- 208 - Record patient communication preference

Allow Direct messaging and SMS messages to be options for patient communication.

- 302 - Medication, allergies, problems reconciliation

Allow patient to participate in and review the reconciliation, consistent with our comments to 105-107 and 204D.

- 303 - Provide summary of care record on transitions

Allow patient to access the summary.

- 304 - Expand transition of care record

This requirement should not be deferred to the future, but made a part of Stage 3.

- 127 - Maintain interdisciplinary problem list and versioning

This should be linked to the patient's medical home and PHR, if any.

- 401B - Patient-specific immunization recommendations

Allow patient independent access to immunization recommendations.

- 402A - Public health reportable results submission

Provide for notice to patient if such a submission is made about him/her.

- 403 - Electronic disease surveillance registries

Provide for notice to patient if such a submission is made about him/her.

- 404 - Electronic cancer surveillance registries

Provide for notice to patient if such a submission is made about him/her.

- 405 - Electronic ACO surveillance registries

Provide for notice to patient if such a submission is made about him/her.

IEWG

- I03 - EHR batch export to reduce vendor lock-in.

Batch import capability should be required as well.

Additional Questions

- MU04 - Privacy and consent for sensitive health information

Centralized consent should be enabled.

- MU05 - Enable external apps

This should be permitted using a variety of approaches to authentication and communication, including OAuth, UMA and HData.

- QMWG06 - Patient Centeredness: Broaden stakeholder input

Open source software should not be disadvantaged in this process, so that patients can make choices about how to store and share their data.

- QMWG07 - Patient Centeredness: Patient reported clinical quality measures

Any data collected by patients in PHRs could be used in this process with appropriate metatags declaring data provenance and time stamps.

- QMWG08 – Patient-Generated data

While patient-generated data could perhaps be tagged as such, it should be included in any quality measurement schema. After all, much of what we consider provider-generated data is simply information reported by a patient and transcribed by a provider. The patient is the most highly qualified expert on his or her own health, and his or her own experience of the health care system. Patient-generated data is a critical element of any approach to quality measurement within the health care system.

- PSTT01 - NSTIC

HITPC should promote the use of non-healthcare credentials in healthcare.

- PSTT03 - Should external authentication providers be used by EHRs

Yes.

- PSTT04 - Provider education

Provider staff should be trained on the rights of patients to access their own health care information as part of their HIPAA training.

- PSTT05-8 - Audit logs and accounting for disclosures

Patients are inconvenienced and costs go up when commodities like logs and authentication are made specific to health care. We would encourage the use of existing IT standards from outside health care, if any.

We look forward to seeing the next iteration of the Stage 3 rule incorporating these recommendations, which will enable the further transformation of the health care system to a patient-centered, collaborative system of care.

Please do not hesitate to contact us should you or your staff wish to discuss these recommendations further.

Thank you for your consideration.

Sincerely,



Sarah Krug
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