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# Health Information Technology Standards Committee Precision Medicine Task Force Report of the April 13, 2016, Virtual Meeting

## Name of ONC Staff Liaison Present: Maya Uppaluru

## Purpose of Meeting: Not stated

## Meeting Outcome

Task Force Co-chairperson Andrew Wiesenthal noted the number of absences and reported that David McCallie had submitted comments on the presentation slides. Wiesenthal announced that he and Task Force Co-chairperson Leslie Kelly Hall will report at the up-coming HIT Joint Committees meeting. He showed slides prepared by staff on interoperability pathways critical to PMI. (The slides will be used in the presentation to the Joint Committees.) The pathways were categorized as near-, mid-, and long-term. Mitra Rocca said that her name was not on the task force roster. Staff will check and correct the roster as necessary.

Wiesenthal talked about the slide labeled near-term recommendation (2016): focus on EHR data first (labs, meds, etc.). Dixie Baker asked about data format and data models, and the meaning of data export. A staff member referred to having received comments from McCallie and Josh Mandel on data export. Baker said that the recommendations were not clear on the meaning of format. The export model will be the EHR model. Eric Rose expressed confusion about the near-term slide, wondering about the format for individual data. Wiesenthal said that individuals will be collecting and uploading data in a variety of ways, not all of which will be identical or comparable to EHR data models. Rose referred to the standardized message. Wiesenthal indicated that the recommendation could be made more restrictive. Uppalura reminded the members that given the many unknowns with the PMI, the recommendations should focus on options. Gil Alterovitz suggested listing acceptable candidate standards, which will limit and constrain the choices. Wiesenthal agreed. Baker recommended export in standard EHR format that can be anticipated by recipients. Rocca talked about adding CDA. Betsy Humphreys observed that the two parts of the slide—HPO and individual data—may be confused. Anyone writing an API should write to a common output format for an EHR. Wiesenthal will work with staff to change the slide. He summarized that the recommendation is that everybody will be constrained to using the EHR export format followed by translation by the recipient. Joyce Sensmeier commented that although FHIR will be essential, it is a rapidly emerging standard. Wiesenthal said that all of this will evolve. Rocca suggested that additional models be named. Wiesenthal told the members to submit names of others to staff.

Wiesenthal directed their attention to the slide on mid-term focus (2017): enable data gathering from other independent non-provider sources. He opined that some policy, beyond standards, may be necessary. Rose said that this also applies to the flow from EHRs to the PMI cohort. According to Wiesenthal, it would depend on the relationship of the HPO and the participant. Baker observed that the discussion was mixing identity and matching with consent and permission. Identity is the greatest challenge. Wiesenthal agreed to separate the topics, saying that policies are needed on authorization. He asked staff to deal with this separation. Uppaluru interjected that the goal of the slide was how to get to a complete record for a patient: What are the data sources? Rose recommended that they propose the creation of a unique participant cohort identifier number and determine how participants wish to handle their numbers. Such an identifier would also serve in the broader health care environment. A VA representative described that the separate codes for bionomic, genomic, survey, EHR and other data are linked to a master index under guard. Wiesenthal summarized the discussion. Three related concepts require separate recommendations: the desire for more complete information than contained in EHRs; a need for secure identification and matching of individuals; and consent for matching and linking data sources. He said that methods for matching and consent are out of scope. Veterans reportedly do not want their identification numbers exposed. Matching is out of scope because the HITSC and HITPC have worked on the topic previously. Members agreed to reference those recommendations and materials on identify matching.

Wiesenthal moved to the slide on long-term (2017-2018): return an individual participant’s aggregated data from multiple sources, and eventually research results. Stephen Keating declared that this return should begin immediately. Humphreys reported that NIH wants to give data back to PMI participants as soon as possible, beginning with summaries of descriptive data submitted by participants. Wiesenthal agreed to change the dates on the slide.

Keating suggested differentiation of raw data and analysis so that raw data could easily be given back to participants. Uppaluru pointed to the complexity of the issue, saying that others in the federal government are working on it. Someone said that there is a current restriction on provision of raw data. Baker observed that participants also have a right not to receive their data. Wiesenthal said that the idea is to have choices on whether to receive data, and how and when to receive the data. He noted the difference between binary data and variable ranges based on methods of collection. These are granular preferences. Rose said that participants should be able to obtain their genomic sequencing and genetic testing data, which are the most useful information for the duration of their life spans, going beyond the life of the PMI. To be useful, these data must be computable. Baker observed that access to these data, rather than their receipt, is the point. Rose added that in addition to access, participants should be able to grant access to others of their choosing.

## **Next Steps**: Staff will revise the slides based on the discussion for the co-chairpersons to use in reporting to the HIT Joint Committees. The task force will meet April 21.

## Public Comment: None

## Flag to ONC Staff for Coordination: None

## Attendance

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Name | 04/13/16 | 03/30/16 | 03/16/16 | 02/26/16 | 02/12/16 | 09/18/15 | 09/10/15 |
| Andrew M. Wiesenthal | X |  | X | X |  |  |  |
| Andrey Ostrovsky | X |  | X | X | X | X | X |
| Betsy Humphreys | X |  | X |  |  | X | X |
| Christina Heide | X | X | X | X | X | X | X |
| David McCallie, Jr. |  | X | X | X | X |  | X |
| Dixie B. Baker | X | X | X | X | X |  |  |
| Eric Rose | X |  | X | X | X | X | X |
| Gil Alterovitz | X | X |  | X | X |  |  |
| James Breeling | X |  | X | X | X | X |  |
| Jon White |  |  | X |  |  | X | X |
| Joyce Sensmeier | X | X | X | X |  |  |  |
| Ketan Paranjape |  | X |  |  |  |  |  |
| Leslie Kelly Hall |  | X |  | X | X | X | X |
| Mary Barton |  |  |  |  |  |  | X |
| Matthew Might | X | X | X |  | X |  |  |
| Maya Uppaluru | X | X | X | X | X | X | X |
| Mitra Rocca | X | X | X | X | X | X | X |
| Stanley Crosley |  |  |  |  |  |  |  |
| Steven Keating | X | X | X | X | X |  |  |
| Teresa Zayas Caban |  |  |  |  |  |  |  |
| Terry Rauch |  |  |  |  |  |  |  |