|  |  |
| --- | --- |
| **Participant** | **Attendance** |
| Anita Walden - Mtg. Facilitator/Project Co-Facilitator | X |
| Karen Ritchey - Note taker | X |
| Russ Leftwich, Co-Leader | X |
| Susan Matney | X |
| Peter Goldschmidt |  |
| Ed Hammond | X |
| Laura Heerman |  |
| Sarah Ryan | X |
| Tom Kuhn |  |
| Seth Blumenthal | X |
| Rachel Richesson |  |
| Frank Minyon |  |
| AbdulMalik Shakir | X |
| Maryam Garza |  |
| Elise Berliner |  |
| Jaspreet Birk | X |
| Amy Nordo |  |
| Chrystal Price | X |
| John Roberts | X |

X = in attendance

**Next Meeting Agenda**

* Finalize Questionnaire
* Discuss January meeting

**ACTION ITEMS**

**Everyone** – Please review the Questionnaire posted adjacent to these Minutes and provide feedback to:

Jaspreet Birk [jaspreetkbirk@gmail.com](mailto:jaspreetkbirk@gmail.com) and Anita Walden acwalden@uams.edu

* **Anita to** Post Questionnaire on the Wiki.
* **Anita** to Send White Paper to CTO Wayne Kubick.
* **Russ** (post mtg change) Explore changing January meeting time

**Previous Weeks Action Items / Status**

·    **Anita** will follow up with HL7 to find out if a brief mention of the Registry Project can be placed in the January Newsletter with plans of an article for the May newsletter

* ***Too late for the January HL7 newsletter, but blog and/or bi-weekly article are doable***

**Agenda**

**Attendance -** Karen

**Approval of Meeting Summary –** Anita

*Posted:*[http://Wiki.hl7.org/index.php?title=Registry\_DAM](http://wiki.hl7.org/index.php?title=Registry_DAM)

**Review of Agenda –** Anita

**Hot Topics**-Group

**White Paper Status –** Seth and Rachel

**Agenda for** (January 19th Q4)- Group

**Storyboard Template Review – see document posted adjacent to Minutes**

*Interview Template Concept DRAFT*

o    Registry Category <Electronic Processing Only>

o    Purpose of Registry

o    Actors in Registry-dropdown list of (nurses, study coordinators, physicians….)

o    Data Sources

o    Process Data – (What is the work flow from data collection to storage)

o    What Registry does with data (Process once data is in Registry Custody)

o    Consent Requirements (Electronic Consent, Paper Consent, Verbal…)

o    List of Data Elements

o    Follow-up Required

o    Use of Registry or 3rd party Vendors for Data Processing

o   Data Exchange mechanisms

o    Data Exchange Partners (Clinics, Government, Other Registries….)

o    How various Registries handle

o    Frequency of Data Collection

o    Standard Data Elements

o    Name of Common Data Model

**Summary**

**Attendance – taken & noted above**

**Approval of Meeting Minutes (November 16, 2016)**

Motion made by Anita/AbdulMalik to approve November 16 minutes,

2nd Seth

Abstentions – 0

Nay – 0

Yea – 9

Minutes Approved.

**Hot Topics / Other Updates**

* Clinical Registry conference tentatively scheduled for May 10 – 11 in Chicago.

*Potential Conflict: HL7 meeting, May 6 – 12, in Madrid.*

* Anita notes: PCPI report now available. Link to PEW Registry Report below. *(will be available in a couple of weeks)*

<http://www.pewtrusts.org/en/research-and-analysis/fact-sheets/2016/11/next-steps-to-encourage-adoption-of-data-standards-for-clinical-registries>

**White Paper Status**

* Posted to Wiki site
* Sent to co-chairs, CQI and Public Health - extended the date for comments
* Suggestion: Send to Wayne Kubick, CTO (Action)
* Feedback received Russ helpful
* Other considerations: Submit to a journal? Further discussion needed to determine which journal, as well as scope and content of paper. Potential publication in journal would be successful in reaching wider audience.

**Agenda for January 19th Q4 meeting**

* HL7 recently schedule a meeting with CMSS to take place on Thursday afternoon which is a conflict with the CCRF meeting .– Russ, and others will be unable to attend.
* Russ will check with Lillian re: CIC agenda and see if there are any open quarters.

(Action)

* Tom is good with move, Ed has internal conflict and Tuesday is not preferred.

*Proposed Topics for Agenda:*

* Critique DAM – identify work to be done
* Russ: If questionnaire is done and responses are back, would be worthwhile to review
* Still on right track? Check to see if aligned - HSPC
* CIC meeting planning for July – harmonization/modeling of data elements

**Storyboard Template continued – (See Template posted adjacent to these Minutes)**

* Category: *Data Processing* is broken down further into Acquisition, Submission, Transfer/Transport.
* Consideration Perspective of Form’s User: Submitter, Registry or Vendor?
* Category: *Work Flow* is too broad. Changed to new header for Data Processing section.
* Category: *Consent Requirement*. Modified with Opt in, Opt out and Other.
* Category added: *Authorization to Access Data in Other Systems*. Data Use Agreement or 3rd party? Type of Agreements: HIPAA, Data, Business or Other? Patient consent forms not necessarily at registries, varies greatly.

**ACTION:**

* Make Questionnaire/Storyboard Interview Template available to group for comments. *(Posted adjacent to these Minutes).*
* Consider: 1 questionnaire or 3 – one for each group?
* Post on Wiki
* Send to CTO Wayne Kubick
* Explore changing January meeting time

**Next Meeting Agenda**

* Finalize Questionnaire
* Discuss January meeting

**NOTE –** Referenced Questionnaire/Storyboard Interview Template is posted adjacent to these Minutes (Wiki/CIC/Registry DAM).

Next meeting – Wednesday, December 14 @ 9 AM (EST)

Submitted by: Karen Ritchey