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

X = in attendance

**Next Meeting Agenda**

* White Paper
* Review of the Registry Questionnaire Template Draft

**ACTIONS:**

**Seth** volunteers to refine initial 7 categories described above (from previous minutes).

Finalize White Paper (**Seth** and **Rachel**)

Outline for Template

Get word out – Newsletters, etc. (**Seth**, **Amy**, **Chrystal** and **Anita**)

Anita: HL7 newsletter

Seth: PCPI announcements & health care constituencies

Amy: Health care group, NEHQ newsletter, blogs

Chrystal: Trauma groups, WHO

Registry Types – **Seth** will refine (clinical, maturation, etc.)

**AGENDA:**

**Objective -** *to review the plan for writing the story scenarios and to start brainstorming a template to be used to interview the Registries*

* Approval of Meeting Minutes
* Review of Agenda
* Hot Topics
* Update on Whitepaper – Seth & Rachel
* ~~DAM Story Scenario Writing Plan – AbdulMalik~~ **not present**
* Interview template - Brainstorm

**Approval of Meeting Minutes (October 19, 2016)**

Motion made by Anita Walden to approve Oct. 19 minutes, 2nd Seth Blumenthal.

Abstain – 2 (Tom Kuhn and Chrystal Price not present for meeting)

Nay – 0

Yea – 7

Minutes Approved.

**Hot Topic - Other meetings attended regarding registries, or comments, that may prove useful**

Seth

* HL7 Interoperability meeting, Baltimore – good session about Registry Needs

Ed:

* When does it stop being a registry and start being a database?
* Need to get the word out about what the Registry Group and their activities

Chrystal

* ACS Clinical Congress – several groups trying to accomplish same things developing data elements and harmonization or sharing of information across Registries.- This Registry Initiative is Important
* Internally – Cancer Registry meeting – standardize data elements

Rachel

* There is Cancer registry. They may have a list of data elements or questions, Cancer checklist…

*Suggestion:*

Get more information out about the work being done by the Registry Group

**AGENDA ITEM #1**

**Status of White Paper *(per Seth and Rachel)***

* In draft form with Rachel’s edits and Anita’s comments. Final draft is near – Seth will pass around White Paper one more time.

**Decision:** Post White Paper “as is” after edits have been made. Leave comments and post on Wiki and send to Working Groups. List Rachel and Seth emails as contacts for feedback.

**AGENDA ITEM #2**

***Discuss Approach for Storyboards***

* Review of Storyboard Types from last meeting (Actors, Process Data, What Registry Does with Data, Consent Requirements, What to do with it, Follow-up and How Various Registries Handle) and Categories (Large, Electronic, States, Rare Disease, Post Market, Medium Size and Government).

*Suggestion:* Approach and Interview 1 or 2 from each category of Registry Types. Seth who can recommend who to interview and will review the categories of Registries. Rachel suggested using students to conduct interviews – need a template to interview the Sites

* Discussion: Who to reach out to? Refine categories of types of Registries.

*Suggestion:* Per Seth – categories should include levels of maturity, quality, etc to identify the Registry categories.

**INTERNAL ITEM – Meeting minutes are now posted on the wiki. Should we** post minutes on both Wiki and Web? Check requirements.

* Discussion continued: Initial categories are good. Consider putting Rare Disease on hold so as not to confuse issue – so much to work with.

ACTION: Seth volunteers to refine initial 7 categories described above (from previous minutes).

Concepts for Template Questions

* What Data Is collected
* Purpose of the Registry
* Who, When, How and Why
* 3rd party
* Sharing with whom

Other Suggestions:

* Early screening interview
* Funding of registries – organization revenues
* Screen for Impact

Summary of Agenda Item

* Purpose and importance of the registry
* Different categories
* Collection of data (defining registry and sharing) and
* Add additional questions or questions related to the major data collected; and,
* Use third-party vendors (need content and structure form or create a template that someone can use for interview)

Interview Template DRAFT

* + Registry Category <Electronic Processing Only>
  + Purpose of Registry
  + Actors in Registry-dropdown list of (nurses, study coordinators, physicians….)
  + Data Sources
  + Process Data – (What is the work flow from data collection to storage)
  + What Registry does with data (Process once data is in Registry Custody)
  + Consent Requirements (Electronic Consent, Paper Consent, Verbal…)
  + List of Data Elements
  + Followup Required
  + Use of Registry or 3rd party Vendors for Data Processing
  + Data Exchange mechanisms
  + Data Exchange Partners (Clinics, Government, Other Registries….)
  + How various Registries handle
  + Frequency of Data Collection
  + Do you use Standard Data Elements
  + Do you have a Common Data Model

Agenda Completed.

**ACTION:** Get the word out.

*Suggestions*:

Anita: HL7 newsletter

Seth: PCPI announcements & health care constituencies

Amy: Health care group, NEHQ newsletter, blogs

Chrystal: Trauma groups, WHO

**ACTION:**

Finalize White Paper (**Seth** and **Rachel**)

Outline for Template

Get word out – Newsletters, etc. (**Seth**, **Amy**, **Chrystal** and **Anita**)

Registry Types – **Seth** will refine (clinical, maturation, etc.)

**Next Meeting Agenda**

* White Paper

Next meeting – Wednesday November 16 @ 9 AM (EST)

Submitted by: Karen Ritchey