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

X = in attendance

**Next Meeting Agenda**

* Meet with Seth about the Plan/Approach to writing Storyboards
* Draft an interview template
* Discuss how to Connect with Registry Owners
* Update on Whitepaper

**ACTIONS:**

**Anita** will review PSS to remind group of the Registry Scope

**Anita** and **AbdulMalik** will review the whitepaper by next Friday

**Agenda:**

**Next Steps for DAM** – AbdulMalik Shakir

Discuss Approach for Storyboards

**Status of White Paper**

\*Circulate for review before posting on web

**Meeting Summary**

**Status of White Paper**

* The whitepaper has been sent to Anita and AbdulMalik to review and once those comments have been incorporated the whitepaper will be placed on the CIC website for broader review

**ACTION: Anita** and AbdulMalik will review the whitepaper by next Friday

**Discuss Approach for Storyboard – AbdulMalik Shakir**

* The objective of the discussion to come up with an approach to create the storyboards. It will require understanding the scope of the storyboards and how to categorize the content so we can ask for volunteers to contribute.
* *Suggestion:* Type-Subject
  + Need to know:
  + \*Actors in Registry
  + \*Process Data
  + \*What Registry does with data
  + \*Consent Requirements
  + \*What to do with it
  + \*Followup
  + \*How various Registries handle
* *Suggestion:* Registry operators who operate multiple registries:

\*Combine data – develop consistent data definitions

\*Create domain analysis models

* Elise: National Academy of Medicine has meeting today which will include successful use of real world evidence… getting data from real world sources. She will share email link.

National Academies meeting today, you can listen over webcast: [http://www.nationalacademies.org/hmd/Activities/Research/DrugForum/2016-OCT-19.aspx](https://urldefense.proofpoint.com/v2/url?u=http-3A__www.nationalacademies.org_hmd_Activities_Research_DrugForum_2016-2DOCT-2D19.aspx&d=CwMGaQ&c=27AKQ-AFTMvLXtgZ7shZqsfSXu-Fwzpqk4BoASshREk&r=a8qVgF5rsxfZqzAs9uqHuJPE-KTXTY9R2rB48aU5q6g&m=F-8L9LHOwUybfc_peyp0jywTcRzQX9U-phCMj2CGd30&s=3sLiTGV6LLGGhD9AwXYA1p6jxX6clUAbFhCqekoc12c&e=)

* *Comment:* Concern was expressed that the process for designing storyboards would require registry owners to find commonalities and differences. Can be time consuming and expensive. Must define parameters and Purpose.
* *Suggestion:* Project Team will create a questions to ask of the registry groups for Seth to send out to solicit information
* Other Use Cases to include: Data can be collected many ways:
  + \*Wearables
  + \*Mobile
  + \*Non-traditional
* There are categories of information that need to be flushed out perhaps we can write the storyboards around these use cases:

**Storyboard Categories:**

1. Collection of Source Data
2. Defining the Data
3. Registry Data Submission
4. Sharing information

* Rachel suggested involving students in the activities but they will need a structured framework to work within.
* *Suggestion:* The Project Team Structure questionnaire for interview use

\*Create Storyboard - different registries and find commonalities

* Suggest to identify Registries to help provide the information for the storyboard

Mature Registries who may have much of this material in place

Ex: Ophthalmology, Cosmetic surgery, TBT, Cardiology, Thoracic Surgery

* To address the concern that we can’t talk to every registry let’s interview one or two registries of various types.

*Registry Types*

* + Traditional Large Registry groups (ACC, ACS…)
  + Registries who are totally electronic (Ophthalmology)
  + State Registries (cancer registry)
  + Rare Disease Registry
  + Post Market
  + Medium Size (Pregnancy Registry OTIS)
  + Government (VA)

Summary of Agenda Item

***Decisions*:**

* Define Storyboard scope – collect clinical data and narrow down to disease specific.
* Interview Different Types of Registries
* To start… create story board around

1. Collection of Source Data
2. Defining the Data
3. Registry Data Submission
4. Sharing information

* Create an interview template that can be used by students
* Talk to Seth Blumenthal about the approach and the registries to contact
* Write storyboards
* We will work with Rachel to create student projects from this activity

**Action Items:**

Anita will review PSS to remind group of the Registry Scope

**Next Meeting Agenda**

* Meet with Seth about the Plan/Approach
* Draft an interview template
* Discuss how to Connect with Registry Owners

Next meeting – Wednesday October 26 @ 9 AM (EST)

Submitted by: Karen Ritchey