



11/7/17 – Meeting Minutes

## Data Use & Publications Working Group Meeting #1

### Meeting Attendees:

David Miller (Boston), Chris Moertel (Minnesota), Justin Jordan (Boston), Nicky Ullrich (Boston), Xia Wang (Moffitt)

1. Describe the scope of work for Data Use and Publications Working Group
  - DM: Group is for as needed basis
  - DM: Someone else can take the lead and guide the discussion of the working group
2. GeM Consortium model - Project GENIE model
  - DM: It would help the rest of the people in the consortium if we said what we were going to do in terms of publications
  - DM: Is Project GENIE something we could adapt as our model? Do we want different levels of contribution? For example, sites who contribute the most are at a higher level.
    - CM: When we do small clinical trials, we list authors by how many patients they contributed. Those who contribute more to the manuscript are moved to the top. My main question is...are we going to have some kind of common database or common usage, and if we have a common database and everyone shares, then that will wash out the number of tumors contributed. We'd almost have to do this by a case-by-case basis. We are part of the Synodos project and there is a common database run by Sage. It is embargoed for the group for a certain amount of time. I am open to the embargo system if a particular group has a particular project, but I am also for having the data open.
3. Publications & Authorship Considerations
  - DM: On the last SC call, I talked about that I would foresee a process of an embargo period to protect the groups that have collected a good amount of retrospective data. Say they collected 3 dozen samples, once the data is available for them (methylations, pattern data, etc.), then they can have an embargo period and can publish a separate paper. After 6 months, the data would become part of the hosted database at Sage, and the other consortium members would have access. If there are groups that want to waive their embargo, they can.
    - JJ: I think that seems reasonable. I am trying to figure out how much time is needed for data analysis and publication.
      - DM: I would be ok with 12 month embargo period too.
      - Everyone else in agreement
  - DM: We want to come up with most practical model that balances needs of sites and the consortium as a whole. In reality, people will realize that in terms of publishable units, the smaller studies don't really have a lot of value, and it's only through the much

larger studies, that there is a significant publication, but I want to do what's agreeable to the group.

- JJ: I like this perspective.
- DM: Let's say Massachusetts General Hospital has had a significant number of samples submitted and they want to publish something during the embargo period...an outline of the study for the rest of the consortium would be good. Should we create a web form where they can put a title and short description of project with authors? We can keep this info on the website.
  - NU: Good idea because you don't want people querying the data with the same question. We want to make sure there isn't significant overlap with what people are intending to do.
    - Do Data Use people need to review requests?
    - I've been in groups where writing a blurb and analysis plan is important so we can have a little bit of control over the data.
      - DM: Do we want people to submit relevant information of their project, and we'll have a phone call with them to keep track of what they're doing?
      - DM: We could have a GeM Consortium part of website with descriptions of the projects going on. Is it better to see what everyone is working on? Or do we want this group to give a stamp of approval?
  - DM: I would like to come back to SC with recommendation of what we should do
  - NU: David, you can decide if you want to have control over what types of queries can be done.
  - DM: Is everyone on the call open to the idea that we would act as a review committee?
    - XW: A review committee is helpful because the consortium goal is to encourage people to collaborate and to encourage the final results. There should be some sort of mediation role.
    - DM: If we were functioning in that role, we could facilitate collaborations during the embargo period – for example, if two groups have similar ideas. If everyone wanted to get together and do everything together during the embargo period, that would be great too.
    - DM: We could serve the role of reviewing projects for scientific rigor to provide feedback, and also make sure other groups know what everyone's doing. We would need to know the scope, how many samples, and analysis plan.
    - DM: If you are all ok to have intermittent meetings to review projects, then that's ok.
    - XW: Would you also like to incorporate SC people to contribute? How many people are in the Data Use and Publications working group?
    - DM: This group is a pretty small group. If we asked for SC to review things for scientific merit, it might sort of bog down the process. That would be my only concern. But I am open to your suggestions.
    - DM: Should we vote on whether we'd like to have Data Use and Publications working group to function as the scientific review group, and this would be a delegated role from the SC.

- XW: I would say yes. As a group, do we have the knowledge of bioinformatics for example?
      - CM: If we don't, we can recruit people in to do it.
      - XW: If we can recruit people, that sounds good.
      - DM: We can do this on an ad hoc basis and get someone appropriate on the call.
      - XW: I am for that.
      - DM: Who is in favor that we would have people on the call now and those who can't make it can be the review group?
        - Everyone in favor. We can have this as a meeting point on the next SC meeting.
- CM: Are we going to make a recommendation regarding the embargo? I heard a general conclusion earlier that 12 months was appropriate.
  - Everyone in agreement
- DM: Need to agree about submission form for proposals and what fields are necessary. We can mock something up to send by email so you all can provide suggestions or edits.
  - Everyone says this sounds good.
- DM: We should also get out in writing – what are we going to do in terms of a consortium-wide publication (in terms of authorship and credit)?
  - CM: There should be a general agreement among consortium members. The consortium and member institutions will be acknowledged in every paper that comes out. But after that, it will come down to scientific contribution.
  - DM: I would like to model this after what Project GENIE said. With using the data set, cite the consortium. Tagline about the anonymous donation as well.
  - DM: How are we going to mediate disputes about contribution? Does this group want to get involved with sorting this out? There are numerous variables in measuring contributions. How can we manage this? Project GENIE had an alphabetical list of authors and where they are from; however, this is not an analogous situation because all of the GENIE partners were pretty equal. We may have more inequalities in this consortium.
  - DM: We should agree on whether or not the most important thing is that the authorship reflects relative contribution.
    - JJ: Sounds reasonable
    - XW: A list of elements to weigh contributions should be considered
    - DM: Among our working group, we can draft up a half-page description on how this may work.
    - NU: The way that some groups do it is that they include specific author names of those who have contributed the most for the project.
    - DM: We need to decide among the various options on how we should do things.

- DM: We can come up with a variety of options and have SC vote.
  - DM: What do you think option A and B should be? A – try to figure out who had biggest contribution on behalf of the consortium, and then list everyone else who contributed.
  - NU: Alphabetical option is there as well. You may have multiple people at an institution. There should be some requirements like each institution has one person. Don't want to end up having multiple others from one institution.
  - JJ: At MGH, Scott has been worried about the amount of people looped in to the project. Want to make sure everyone is rewarded for their efforts.
  - NU: For authorship, they need to do more than just letting us know about a patient. There should be authorship requirements.
  - DM: Need to find 2 or 3 publication models as examples before writing it all out.
- DM: Use of GeM Consortium data by people who are outside consortium (people who are qualified investigators). If they want to have access to the data or limited data set, what kind of rules of engagement would we have? I would assume people would submit a request and we would give approval. Does this make sense?
  - Everyone thinks it's reasonable
- DM: Would it also be reasonable to say that we wouldn't accept requests from outside investigators until we've completed our consortium-wide publication?
  - Everyone in agreement
- DM: Next meeting should be after the next SC meeting.