COVID-19 Statewide Meeting 4/24/2020

Updates from Dr. Dodani and Amy Adams

- Amy suggested that we may need to adjust agenda to bring everyone up to speed.
- There has been a lot of activity on trying to identify funding.
- Drs. Dodani, Johnston, and Brown spoke together yesterday and everyone was onboard with this plan.
- Amy took this back to the GMU's VPR—they are looking at institutional funding sources.
- Final decision on funding won't be made until later this afternoon on their end.
- May need to use this meeting to focus on how funding should be allocated.
- Proposed that GMU, EVMS, UVA, VCU, Vibrent would each kick in $200,000.
- We can then pick up this conversation over the weekend or early Monday.
- Institutions need to understand what their investments will be used for—how would it be allocated?

Further Discussion of Other Topics

- Questions about data variable list provided: there are identifiers there, indicates that we would be consent patients, which may be very difficult.
- Sarah clarified that this is a preliminary list—nothing is set in stone as we continue to refine based on group expertise.
- Feedback—concept needs to be clarified.
- VCU may have issues with contributing financially to this.
- Need to get the details first before any money is put forward.
- Dr. Brown suggested that if we want to put money someplace it might be to get more participants in the existing UVA registry—put money into community organizations in the regions to get wider participation, particularly in at-risk communities.
- Documents you've seen are very much brainstorming because we are coming at this from so many directions.
- Want to maximize enrollment across the state.
- Johana clarified that cross site research studies can certainly happen, but their data security plan does not allow for data to flow directly.
- UVA is already working with the N3C project—for more information: https://vimeo.com/407596298/c58fcf081a
- Dr. Sill is very focused on the clinical practice side as a pulmonologist.
- Hopes to see a way to funnel all data into one location in as comprehensive way as possible.
- Dr. Brown explained that bringing data together from these different sites is not a simple matter because of the different data structures.
- iThrive is designed to be a *population-based survey* (not limited to COVID-19 patients).
- These questions of bringing data together are being looked at on the national level.
  - One example is LOINC code discrepancies.
  - Then harmonization is another major issue.
- Tomas suggested that since we are at the peak, it makes most sense to focus on retrospective data—we are already behind.

- On the other hand, Dr. Sill emphasized that COVID is here to stay, until we have a vaccine or a more long-term solution—it's important to push forward.
- Immediate needs vs. long terms needs—need to better understand who is at greatest risk if there is another peak.
- Also thinking about long term health impacts.
- The strength of the Vibrent tool can allow us to hopefully push this out quickly.

Big Picture & Where to go from here

- Need to collect data as part of a statewide registry.
- Funding is a major factor.
- Where should we go from here?
- Question from Johana—what are partners being asked to do? Would it be a data pull? Would it be data entry? What is the time and effort? Need clarity from PJ around how this would be done.
- If there are any questions that should be added to the UVA registry, please send them to Johana and Don. Focus on community partnerships as a source of participants—to get the word out about the existing registry—want to get broad participation.
- Then eventually we may be able to bring that together with medical record information.
- Reaching those community groups would be a big step forward.
- Given the existing study that's underway, is there a way to unite this with Vibrent?
- The distinction throughout these conversations has been the citizens vs. patient data. It makes sense to think about them separately. Thinking about the fact that there is already something up and running, how do we support what is going on, while then developing something unique?
- Johana encouraged clinician partners with an important question, to move forward with it. We can pull in potential site PIs throughout the state.
- Does the UVA study have the ability to assimilate clinical/EMR data? Not currently.
- Two different repositories: inpatient EMR data could be pooled, and then feed all the outpatient/citizen data into the UVA registry.
- There is already a national level (N3C) doing the clinical data integration piece—we can take advantage of that and participate.
- Should we be doing state registry if we are already doing a national registry? State registry may still be useful—may be able to answer more targeted research questions and integration may be easier as well.
- Don suggested that having the national infrastructure will enable a statewide registry—by participating in the national structure, that will make a state registry easier. Let's take advantage of what is already being done on the national level.
- What is the timeframe for NIH tools? Possibly weeks away.
- In those weeks we can work on funding so that once the tools are available we can put it together fist.
- Need to hear from Vibrent on how they plan to combine this data.
- Leads from all the institutions will have a small group call.