



Parkinson's Disease Registry Advisory Committee Meeting Minutes

Date: Wednesday, April 13th, 2022 (4:00 – 6:00 pm)

Location: Zoom (<https://umass-amherst.zoom.us/j/93968180415>)

Materials Provided: Meeting agenda, presentation slide deck.

Committee Members:

Brett Miller (co-chair), Cathi Thomas (co-chair), Dr. Samuel Frank, Lauren Fogarty, Dr. Anindita Deb, Dr. Terrell Johnson, Dr. Glenn Tucker, James Cornell, Matt Keswick

Others Present:

Mary Lou Woodford, Casey Hall

Call to Order by co-chair Cathi Thomas

Roll Call:

- Cornell, not present
- Deb, not present
- Fogarty, present
- Frank, present
- Johnson, present
- Keswick, not present, joined at 4:25 PM
- Miller, present
- Thomas, present
- Tucker, present

I. Welcome

Motion to accept minutes from the 3/23/22 meeting by member Fogarty, seconded by member Frank.

Members present unanimously accepted proposed minutes.

II. Review of Committee Deliverables

Coordinator Mary Lou Woodford guided the group discussion around the deliverable elements.

What is the purpose of the registry?

Member Deb has provided research and thoughts to Mary Lou.



Member Johnson emphasizes a focus on equity and access to accurate data for researchers.

Member Frank: Add access to research and findings for patients. Opportunities to partake in research.

Member Tucker: Take care to avoid any use of the registry for the purpose of marketing to patients. Recommend opt-out for data inclusion in the registry, opt-in for inclusion in research contact.

What design would the committee like to recommend?

Member Johnson: Semi-annual reporting, unclear how to adjust data based on evolving diagnoses. Data over time is important.

Member Frank: Need stakeholder input. Recommend electronic data transfer over paper forms, though retain paper as an option. Adjusting data becomes difficult as duplicates and changes in status are likely.

Coordinator Woodford: We may recommend inclusion of stakeholders in the prepared report, along with other parameters discussed.

Member Frank: Has spoken to a colleague in California involved with their registry and feels that this is very important.

Member Keswick: Who is to be included as a stakeholder? Individual hospital or networks?

Member Tucker: We should also include industry standard information protocols such as HL7 or CCDA.

Member Frank: No need to limit stakeholder inclusion.

What is the functionality of the registry?

The members and Mary Lou discussed the functionality versus the purpose as well as overlap with previous conversation.

Member Keswick: Is there an implementation guide for California?

Coordinator Woodford: Yes. Also should consider security and practices.

What data should be collected?

Member Frank has generated a list of proposed “must have” and “nice to have” data points to be tracked and describes them for the group. See attached document. Some discussed items, such as ZIP code and social security numbers were left off list, but are desirous for inclusion now that the group has discussed privacy in more detail.

Coordinator Woodford has compiled the data collected by California and presents the fields. She points out that California uses required fields and optional fields and that this is an option for recommendation.

Member Frank would like to know how California’s reporting is going and how colleagues feel about the California data fields.

Coordinator Woodford also consider how data will be tracked over time.



The members discussed various elements that might be removed or added to this list and whether they might be tracked over time including occupation, past exposure to toxic materials, death, gender, genetic testing, head injury, psycho-social information, medical record numbers.

The possibility of a post-diagnosis questionnaire, including for patients was raised.

Members Frank and Johnson leave. Quorum is retained.

Coordinator Woodford to follow up with member Tucker regarding data input and output.

How should the data be disseminated?

The members discussed elements of dissemination, including annual reporting and access to data.

How should the registry be implemented?

The discussion returned to triggering events, reporting, and the need for an implementation guide.

What is the projected budget for implementation?

The members discussed the projected budget. Member Fogarty has advanced \$500,000 to \$800,000 thousand as a minimum number.

Member Keswick asks for clarifications about the anticipated costs.

Coordinator Woodford reports that Maryland is working on their own registry and have set a budget of \$828,000.

Member Keswick asks for clarification about the needed staffing.

Coordinator Woodford and member Fogarty describe existing staffing for other DPH-related registries.

Member Keswick suggests proposing an implementation budget and an annual budget.

III. Review Draft Outline of Final Report

Item tabled.

VI. Next Steps

The committee reviewed remaining tasks and meetings to plan for the next meetings.

Motion to adjourn from Fogarty, seconded by Tucker.